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GULF WAR EXPOSURES

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON VETERANS' AFFAIRS
U.S. HOUSE OF REPRESENTATIVES

ONE HUNDRED TENTH CONGRESS

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GULF WAR EXPOSURES

THURSDAY, JULY 26, 2007

U.S. HOUSE OF REPRESENTATIVES,
COMMITTEE ON VETERANS' AFFAIRS,
SUBCOMMITTEE ON HEALTH,
Washington, DC.

The Subcommittee met, pursuant to notice, at 10:00 a.m., in Room 334, Cannon House Office Building, Hon. Phil Hare presiding.

Present: Representatives Hare, Moran, and Brown.

OPENING STATEMENT OF HON. PHIL HARE

Mr. HARE. Good morning. The Subcommittee on Health will come to order. I would like to thank everyone for coming today. Regrettably, Mr. Michaud, the Subcommittee Chairman, had an emergency and isn't able to be here today. I'm Congressman Phil Hare from Illinois. This is, I think, my first opportunity to Chair a Subcommittee hearing, so I hope you will bear with me.

During this hearing today, the Subcommittee will examine Gulf War exposures of veterans. The incidences of Amyotrophic Lateral Sclerosis (ALS) among Gulf War veterans and most importantly where is the U.S. Department of Veterans Affairs (VA) in conducting continuing research on Gulf War I exposures and what they are finding out about the current exposures in Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) veterans. Many of the veterans who served in the Gulf War were exposed to a variety of potentially toxic substances during their deployments.

According to the Research Advisory Committee on the Gulf War veterans, more than 16 years after the end of Operation Desert Storm, a substantial proportion of veterans continue to experience chronic and often debilitating conditions characterized by persistent headaches, cognitive problems, somatic pain, fatigue, gastrointestinal difficulty, respiratory conditions, and skin abnormalities.

The Department of Defense (DoD) and the Department of Veterans Affairs together has spent $260 million on Gulf War illness research. While there have been numerous studies and much research conducted on Gulf War illnesses there are still many unanswered questions. Another aspect of Gulf War I Service is ALS. ALS is a progressive and nearly always fatal disease that affects a person's nervous system. According to the Institute of Medicine (IOM), Amyotrophic Lateral Sclerosis in veterans review of the sci-

entific literature, there is limited and suggestive evidence of an association between military service and developing ALS.

Additionally, in a study sponsored by the Department of Veterans Affairs in 2003, researchers identified the incidences of ALS in veterans deployed to the Gulf as twice as high as the incidences of diseases among those who did not go to the Gulf.

I look forward to hearing from our panelists on these very important issues. I would now like to yield to my friend, Mr. Brown of South Carolina, for any opening statements that he may have. Mr. Brown?

[The prepared statement of Congressman Hare appears on p. 42.]

Mr. BROWN OF SOUTH CAROLINA. Mr. Chairman, if I might, I would like to yield to Mr. Moran for an opening statement. Then I have an introduction I would like to give.

Mr. HARE. Without objection.

OPENING STATEMENT OF HON. JERRY MORAN

Mr. MORAN. Mr. Chairman, thank you very much. I only want to commend this opportunity for us to once again examine the consequences of various exposures and conditions that our military men and women have encountered in service to their country, particularly as it relates to the war in the Gulf.

Over the last 10 years this Subcommittee, this—actually the full Committee has held ten hearings on the topic of Gulf War Syndrome. In the past, I chaired the Subcommittee on Health and this was a significant topic of our agenda and continue to believe that it is important for us to make certain that we learn everything possible from our previous exposure to conditions in the Gulf and to make sure that back in 2002 when we were entering into Afghanistan, we were trying to make certain that our military had learned lessons from that previous Gulf War experience.

Again, I think the consequences of our deployments are significant and real and need to be fully addressed by our Committee, but particularly by VA. So these are important hearings on useful topics, and I am glad to see the seriousness with which we are approaching the Gulf War Syndrome today.

Thank you, Mr. Chairman. Thank you, Mr. Brown. I yield back to you.

OPENING STATEMENT OF HON. HENRY E. BROWN, JR.

Mr. BROWN OF SOUTH CAROLINA. Thank you very much. And it is absolutely a great honor today to be able to be a part of this hearing. And I thank the Ranking Member, Mr. Miller, and the Chairman, Mr. Michaud for conducting this hearing. And I am glad to have you, Mr. Hare, as leading this charge this morning.

Within my State of South Carolina and the Nation as a whole who have served the country during the Gulf War as a Member of this distinguished Subcommittee, it is my duty, it is our duty to provide our Nation's veterans with access to the best healthcare possible. It is our duty perhaps even a moral responsibility for us here today on this Subcommittee to help those brave veterans who have helped defend our great Nation.

Today I have the distinct and dignified honor of introducing someone who answered the call of duty by helping his country

when it needed him the most. And today he comes before us and asks for our help. His name is Brigadier General Thomas Mikolajcik.

For many years my personal friend and great American hero, General Mikolajcik, or General Mik as he is known by his closest friends, has been a leader in the Charleston Community. First as commander of the C–17 Wing Base at the Charleston Air Force base and then as an active contributor to the Charleston Chamber of Commerce Military Relations Activities following his retirement in 1996.

But General Mik's dedication to the Charleston Community would be noteworthy in any case, it is even more impressive when one realized that his focus on the needs of this community comes at a time when he is suffering from a debilitating and deadly disease.

In 2005, General Mik announced that he had been diagnosed with ALS. While many individuals would have immediately withdrawn under the pressure and impact of ALS, the General used it as an opportunity, and with much resolve and endurance doubled his efforts and dedication. In addition to continuing his commitment to the Charleston Community, the General has devoted a great deal of attention to raising awareness within the community of ALS and improving the quality of life for ALS patients and their families. Thanks to his efforts, a new ALS Association Chapter was formed in South Carolina and the only ALS clinic in the State was founded at Charleston Medical University of South Carolina.

General Mik is truly an inspiration to many throughout the Charleston Community, continually thinking of others despite the great challenges he has faced. Numerous studies have shown that individuals who have served in the military have a higher propensity toward being diagnosed with ALS. While the Department of Veterans Affairs has identified ALS as a Gulf War I related disease, cases abound that show the spread of this disease among veterans is much broader.

Indeed, a recent study showed the veterans of all conflicts have a 60 percent higher chance of being diagnosed with ALS than the general population. It has been nearly 70 years since Lou Gehrig made his famous speech and retired from baseball after contracting this horrific disease. And it has been nearly 17 years since the end of Gulf—first Gulf War, and yet little has been done about this disease and even less is known about it's causes.

The work of General Mik has also brought to my attention the growing number of veterans contracting ALS outside of service during Gulf War I. My office is aware of a number of cases in my district from veterans who have developed ALS where the VA has denied their claims because their service was not within the presumptive timeframe of August the 2, 1990, through July 31, 1991.

We don't have a good handle on how many non-Gulf War I veterans have contracted ALS, what military-related risk factors exist and what we can do to decrease the chances of ALS among our veterans and military servicemen and women. This issue is of special concern as we continue to have troops deployed in OEF and OIF.

The story of General Mik serves as a testament to the need for leadership at the Federal level toward developing the comprehen-

sive ALS research program and declared VA/DoD policy ensuring that all veterans with service-connected ALS receive the attention they deserve regardless of whether or not they served during Gulf War I. We need an agency to step up to the plate and lead Federal research into the cause of ALS and how we can better improve it's treatment.

Most importantly, we need to begin these efforts now before more veterans, including General Mik, succumb to ALS. And I thank you, Mr. Chairman. And I also would like to identify his wife, Carmen, who is with him and also his son, John, and Jamie Haywood, who is founder of the ALS Therapy Development Institution. And I thank you all very much for coming.

[The prepared statement of Congressman Brown appears on p. 42.]

Mr. HARE. Thank you, Mr. Brown and welcome General. Our remaining panelists are Anthony Hardie who is a Gulf War veteran. Anthony, let me first of all thank you for coming and thank you for your service to this country. And Denise Nichols who is Vice Chairman of the National Vietnam and Gulf War Veterans Coalition.

So, General, we will start with you and we welcome your testimony. Good morning.

STATEMENTS OF BRIGADIER GENERAL THOMAS R. MIKOLAJCIK, USAF (RET.), MT. PLEASANT, SC (VETERAN); ANTHONY HARDIE, LEGISLATIVE CHAIR AND NATIONAL TREASURER, VETERANS OF MODERN WARFARE; AND DENISE NICHOLS, MSN, VICE CHAIRMAN, NATIONAL VIETNAM AND GULF WAR VETERANS COALITION

STATEMENT OF BRIGADIER GENERAL THOMAS R. MIKOLAJCIK, USAF (RET.)

Brigadier General MIKOLAJCIK. Thank you, Congressman Hare, Congressman Brown, Congressman Moran. I really appreciate this opportunity to testify.

My name is Tom Mikolajcik. I am neither an M.D. nor a Ph.D. I am a PALS. A patient with ALS. I was diagnosed in October 2003. I was given a death sentence and told to get a second opinion while given a prescription for Rilutek which has very limited value. Only by the grace of God am I here to speak with you today and I have vowed to keep speaking until I no longer can.

Military veterans like me face a higher risk of this relentless killer. Fifty percent die in one to 3 years. Another 20 percent die in 5 years. Less than ten percent live to 10 years.

It was learned in 2001 that Gulf War veterans have two times the incident rate of the general population. We discovered in 2005 that veterans going back to War World II have a one point six times higher incident rate then the general population for developing ALS. In other words, any of you in this room that are veterans have a 60 percent higher chance of contacting ALS than nonveterans.

Four short years ago, the VA opened a voluntary ALS registry. It registered thus far 1,993 veterans suffering from ALS. I am sad to say and it is unacceptable to me that only 969 are still alive

today. That is less than 50 percent. I am one of the blessed ones that are still alive.

And ladies and gentlemen that also means somewhere between one and 15 and one out of 30 ALS patients are military veterans. The government must step up to the plate on this issue.

We are currently exposing hundreds of thousands more servicemembers to the elevated risk of this disease. There will be young men, women and families celebrating a return from Iraq and Afghanistan alive, who have no idea that they may soon be facing a certain death from ALS.

We will have to answer those families when they ask what the government has been doing to prepare for this onslaught. For this reason, the government is compelled to assume a leadership role in this issue. If these soldiers were dying in the field rather than quietly at home as a consequence of their service, we would leave no stone unturned. We would use the best of existing resources and programs to make sure they had whatever they needed to survive to ensure no man or women is left behind.

Some say that a lot of ALS research has taken place. My response echoes the famous words of President Lyndon Johnson: "Research is good, results are better." It has been nearly 70 years since Lou Gehrig made his farewell speech and we have basically nothing. One questionable drug in 70 years? What his doctors knew then, what my doctors know today, and what therapies we have are not much different.

How many thousands of private farewell speeches must take place before we realize we are not doing everything we can? Will I have to give mine before an appropriate, large-scale, comprehensive plan to tackle ALS is carried out? ALS is more complicated than a Rubik's cube which is many sided with multiple connections, and various colors like this one. One must consider causes, therapies, biomarkers, genomics, existing drugs, patient needs, palliative care, as well as all avenues of research.

Who is in charge of ALS research today? I have found no one in charge!

[Large rubik's cube placed on witness table.]

What is the strategy for solving this ALS Rubik's cube? I found no strategic plan! Who oversees and is accountable for existing medical research activities for ALS? No one! So, yes, there may be many ongoing efforts into ALS but potential success is thwarted by little cooperation, coordination, and sharing of information. From my viewpoint and understanding, there is no one entity in charge or accountable.

These blocks or boxes represent the ongoing ALS research.

[Various sized wooden blocks spilled on witness table.]

All are separate, none are connected and there is no communication among them. We have underfunded research across the country, each working in their own little box. This approach has been unsuccessful thus far. We need to open the doors of labs and encourage collaboration. There should be no more deaths due to protection of ALS related intellectual property and potential profit. Some of us are in a hurry.

Therefore, it is the government's absolute responsibility to direct research into a full understanding of ALS. In other words, my hope

would be that we not just think outside the box, but totally redraw it; enlarge it to fit the enormity of this horrific disease. Many people come to hearings with problems and needs. I come before you with a solution also. I fully understand bureaucracy's aversion to change particularly within an industry as large as medicine and with the number of government agencies already dabbling and yes, I mean dabbling in ALS research.

Let's look back to 1961 when our Nation made a commitment to put a man on the moon within a decade. One government agency was put in charge and it was supported by other agencies as well as private industry and individuals. My proposal is very similar. It worked then, it should also work now.

This is what I propose: Establish a congressionally directed ALS Task Force with specific milestones and a time line. Within 30 days establish a task force made up of government agencies, ALS researchers, private ALS institutes, patients, and a facilitating team not related to ALS or the medical industry. Within 60 days the task force should recommend which government agency will be in charge and the supporting roles of the other agencies. In other words, an executive agency for the government. Within 90 days develop a strategic plan which outlines all avenues of research to be included. It must be comprehensive, forward looking, and all inclusive. The strategic plan should also outline agency and researchers accountability. An adequate and fair funding stream must accompany this strategic plan.

The decade of the nineties was the decade of the brain. However, we invested too little time and too few researchers on research to understand diseases of the brain, especially such a devastating disease as ALS. Over 30 years ago our country launched a war on cancer. Because of that effort we now have many treatments of this dreaded disease, even some cures. It is time to launch a war on ALS and other neurodegenerative diseases so that we can have effective treatments and cures.

We designated and designed the Apollo Program to put a man on the moon. For ALS we could call it the HOPE Program, Helping Other People Endure. From this day forward this new direction can be a model program that has one government agency designated by Congress which has control and oversight of a lofty objective—solving this ALS Rubik's Cube. There are many private models of leadership to draw upon. Innovations have sprung up driven by those connected to the disease including several which I am involved with. The ALS Therapy Development Institute; the ALS Association of America; the Multiple Dystrophy Association; and the Medical University of South Carolina's ALS Clinic.

These efforts will succeed with public leadership that amplifies their private support into an integrated whole. In the future this model could be duplicated as a test bed for research on other diseases. Because of the similarities among neurodegenerative and neuro-inflammatory diseases, advances in ALS research will likely be relevant to Parkinson's, Alzheimer's, Huntington's and others.

We must prepare to offer our soldiers, sailors, airmen, and marines an opportunity to fight this disease. We cannot simply fight this battle defensively hoping to limit exposure to environmental risk. We must fight it offensively as well with an appropriate med-

ical arsenal. Let's do what it takes to finish off this enemy once and for all. Congress can make the commitment, take the initiative, legislate a new way forward and hold agencies accountable. We have the intelligence, the resources, and the competencies. It is time to apply leadership to the ALS Rubik's Cube to move the campaign in a new and uncharted direction.

Let us have the answer ready for our veterans and the general population suffering from this disease. Let us show them they were worth a real investment and a real plan. Let us redraw and enlarge the box to allow for their futures.

Finally, and probably the easiest task I will ask today, is to immediately establish and fund a national ALS Registry to ensure comprehensive patient information, tissue, genes, DNA, etcetera are available for investigation. Such a registry will facilitate, even stimulate additional research and research collaboration.

This will provide, "HOPE" for future treatment and increased understanding of this disease. But what about veterans like me who may not benefit from these future discoveries and treatments? We owe our veterans treatment now, however limited. Over 5 years ago, the Secretary of Veterans Affairs extended service-connected benefits to Gulf War veterans like me based on the research study results that they had. Since then,new research has shown an increased incidence of ALS among all veterans, 60 percent higher than the general population.

The Secretary for Veterans' Affairs should act now with the same decisiveness and the same concern for veterans by extending veterans benefits to all veterans suffering from this terrible disease. I have attached a copy of the letter I gave to and discussed with Secretary Nicholson on 23 March of this year in Charleston.

Thank you for your attention, for allowing me to speak past my time and for giving me this opportunity to represent veterans. God Bless our veterans! And God Bless the United States of America!

[The prepared statement of Brigadier General Mikolajcik appears on p. 43.]

Mr. HARE. Thank you, General, that was an incredible and compelling testimony. I thank you for taking the time out to come this morning. You are an incredibly courageous person and we will work very hard.

Our next panelist is Mr. Hardie and Mr. Hardie, welcome. And we look forward to your testimony.

STATEMENT OF ANTHONY HARDIE

Mr. HARDIE. Thank you, Mr. Chairman. Mr. Chairman and distinguished Members, thank you for holding today's hearing on Gulf War exposures and highlighting and enduring national significance of these issues. It is truly an honor and a privilege to be here today. And I hope to help voice some of the concerns of the many who are not here to share in that this privilege.

On January 17, 1991 much of America watched Operation Desert Storm unfold on their evening news decisively ending the many long months of the mass troops watchful waiting under Operation Desert Shield. Six weeks and the war was over, but for many of the nearly 697,000 troops who served our overarching Gulf War experience had only just begun.

For those who may not be familiar, Gulf War troops were exposed to a host of toxic exposures often in combination including multiple low-level exposures to chemical warfare agents including from bombed munitions factories and detonated munitions bunkers. Experimental drugs mandated without informed consent like Pyridostigmine Bromide pills intended to help survive nerve agent exposure; inhalation of incredibly high levels of micro-fine particulate matter from the Kuwaiti oil well fire plumes; experimental vaccines like Anthrax, botulinum, and others; inhaled and ingested depleted uranium particulate matter; smoke from the daily burning of trash and feces; multiple pesticides; petroleum products and byproducts.

For some of us who developed lasting health effects from this veritable toxic soup of hazardous exposures, it came while still in the Gulf. For others it did not come until some time after returning home.

Hearing this list of exposures, most people would find it of no surprise that so many thousands of Gulf War veterans became ill, or that so many remain ill and injured today. And it should be no surprise that so many have developed diagnosable serious conditions like ALS, Multiple Sclerosis (MS), and others. What is stunning is that 16 years later, there are still few tangible results that might improve the health of those who became ill and remain ill. And we still have little information of any value to provide the Gulf War veterans or the healthcare providers that might help to improve Gulf War veterans health.

Years were squandered disputing whether Gulf War veterans were really ill, studying stress, reporting that what was wrong with Gulf War veterans was the same as after every war. An incredible amount of effort was put into disproving the claims of countless veterans testifying before Congress of a chemical and other exposures. Some of that negative effort appears to continue even today. It is stunning that after nearly two decades we still have little information to provide the Gulf War veterans who remain ill from their service. It is true that VA does still have an open door for Gulf War veterans to be seen at VA medical facilities, however, being seen is not the same as being treated.

In terms of informing veterans, the VA's Office of Public Health and Environmental Hazards website also contains little information that might be of use to ill Gulf War veterans and to health providers. Much of the information provided is outdated. In July of 2006, the VA's Gulf War review included an article entitled, "Straight From the Source: VA's Environmental Agents Service is Serious About Communicating With Veterans." That issue, more than a year ago, was the last published.

For Gulf War veterans like me whose "Kuwaiti Cough" has never left after having coughed up thick black sputum while still in the Gulf and for several weeks after returning home, the report related to oil well fire smoke and petroleum from this website which seemed to be of particular interest. Perhaps it's lack of usable content, indicative of the lack of attention being paid to these issues, is at least in part related to the fact that it stated principal author was not a leading scientist, but instead a community college communications or journalism student summer intern.

I have heard from countless other Gulf War veterans that they like many before them have stopped going to the VA or have simply given up and have done their best to adapt to the substantial lifestyle changes required by their disabilities, which may or may not be compensated for these disabling conditions incurred in service. Gulf War veterans have had unique and special challenges and in May, a VA report show that only one in four undiagnosed illness claims for Gulf War veterans has been approved.

On a more positive note, I was encouraged during last week's meeting of the Research Advisory Committee, on which I serve, from Dr. Robert Haley and his team describing their research goals of identifying diagnostic criteria for ill Gulf War veterans. Success in achieving these goals should finally help to pave the way for affective treatments. And I remain encouraged by current efforts in the U.S. Senate to provide funding for Gulf War health research within DoD's congressionally directed Medical Research Program focused on treatments that may aid ill Gulf War veterans.

The five-point statement of goals that came from Gulf War veterans more than a decade ago still holds true today. Gulf War veterans deserve then and deserve now an insurance, an exhaustive investigation has been fulfilled to identify all possible Gulf War exposures.

Second, that appropriate scientific research is promptly completed to connect known or potential Gulf War exposures with health outcomes. Third, that medical treatment is bases on that scientific research. Fourth, that compensation is provided to those veterans left disabled by their military service if the health conditions cannot be reversed. And finally, that every effort is made to ensure that never again what happened to the Gulf War veterans be allowed to happen again. For the thousands of living ill Gulf War veterans, it is time to make good on our Nation's enduring promise of caring for those who have borne the battle and their widows and their orphans.

Thank you Mr. Chairman and Members of the Subcommittee.

[The prepared statement of Mr. Hardie appears on p. 46.]

Mr. HARE. Thank you, Mr. Hardie. Ms. Nichols.

STATEMENT OF DENISE NICHOLS, MSN

Ms. NICHOLS. Good morning, Congressman of the VA House Health Subcommittee and to all staffers and attendees. It is indeed an honor to testify at this hearing for all Operation Desert Storm veterans group which reflects only one part of the earlier portion of the Iraq war.

It has been since November 1993 that we have been having hearings on the care and needs of Gulf War veterans. I am a retired air force flight nurse that served on the border of Saudi Arabia and Iraq to care for those wounded in that war. I have continued that duty as a sworn obligation. I am just one of the 697,000 that were deployed in 1990 and 1991. My profession, life, and family have been directly affected, as has been so many others.

The symptoms and life changes I have experienced are not unique. The war changed our health status and our abilities to perform our duties in our chosen life roles through no fault of our own. There are hundreds of thousands of human-case examples both

that were deployed and those that received vaccines and exposures from secondary sources. In 1994, a total gathering of ill veterans and DoD officials and VA officials and university professionals at Bethesda attending the conference held on the Health Consequences of the Persian Gulf War that we Gulf War veterans were different. We were a force of highly trained, educated, and physically fit men and women who served our country in wartime. And even though we were now damaged due to that time in a foreign country, we would not give up and we would find answers and help.

Since then, we have battled for compensation, the exposing of the full truth and nothing but the truth. We have battled for the best care and treatment. Sadly, our war has been facing our own government at times, but as Major Abare an earlier ALS veteran that testified said, "So long ago we did swear to defend against all enemies both foreign and domestic." Sadly this battle seems to be on the domestic end of having a lack of faith and sworn duty for by our government.

The Gulf War veterans community has deteriorated health, rising levels. We have lost too many of our own, but we still stand pushing, prodding, encouraging to get to the truth and to life saving that has been denied for too long. We were met with denials, delays, and resistance, but yet if you had listened and acted many of our lives could have been saved and restored. We ask for the best diagnostic procedures and treatment, we were denied that by lack of truth, at times from our own DoD and government officials.

Some, but not all the truth has been exposed. We felt that more would have been exposed to back up our acknowledgment of the multiple exposures that taken alone or in combination would have a definite affect on our health. We have pushed for the medical examination and diagnostic treatment that would expose the truth held within each of our own bodies. We pushed for the care and treatment we earned by putting our lives on the line to serve our government. Sadly, we have been delayed by forces within our own government. We would win a major fire fight in that battle to face a counter attack or a blocking move. We still wonder, what is this? Is it financial? Is it a policy? Is it protecting some secret? But that answer and the battle our government waged to find the single cause of exposure while we lay wounded still continues.

Those of us with undying spirit and faith would push the wounded each time to raise up and fight for yourselves, your fellow soldier, veteran, your family, and the future soldiers and veterans to reach the goal. Within my longer supplied testimony is a recap of just a few of the insights or snapshots along the road we have traveled in regards to the VA. I have supplied yet another point paper, action plan, or if you want to call it an OP order outlined to fix the broken parts, to move forward the goal of appropriate medical diagnoses and care.

The system was not broken by us, but the result of a multitude of errors complicated by a government or it's employees that denied us the access to the best medical care for whatever reason. It has cost us lives of your fellow Americans, your soldiers, your veterans, your family members. In one 3-month period of grievous data reporting from the VA, we lost 1,000 of us to whatever causes. The

full count is definitely more. This is morally and ethically wrong. In our path we have met many civilian experts that have volunteered to help us out of that morally and ethically wrong situation. Sadly, many of their careers have been negatively affected through their joining the battle. We have officers and individuals that have tried to help from the shadows, well it is time for the all out assault to fix this and have results.

The veterans have led this battle and we are not done. We hope that each of our elected reps will listen to us, join us to fix these problems, remove the road blocks, and move for true action. Let us move forward together to the best diagnosis care, treatment, and compensation before we lose more lives. The veterans have identified something that is critically important and that could affect every citizen in this country through the response to critical hazardous substances, weapons of mass destruction, and environmental exposures. Examples are the World Trade Center, the Anthrax exposures, radiation damage and potential terrorist issues in our own country. The advances made through us could help save lives in the future throughout the U.S. and other countries.

We need the funding and the commitment from all. Will you do your part to correct the errors mismanagement, mis-guidance, obstructions of the past? Will you commitment the funds and the fast tracking of corrective legislation? Will you be the active leaders to investigate, deliberate, and be part of the solution? But please, if you are, you must move quickly and decisively in order to save lives. Help us to streamline the process to get the pin pointed research that is needed. Help us get the right diagnostic care and effective treatment. Do not study, investigate, or deny each of us to the grave. We need the blim research to actual diagnosis and care in a cost and time sensitive manner. We can gain from the clinical data that can be obtained for a cost effective means within each VA hospital and merge it with research efforts to find better diagnostic markers that can be quickly implemented in the clinical area. We need to have our VA care organized so that research for treatment by way of treatment trials can be moved into the clinical area in an expedited manner at true cost effectiveness.

We need universities to cut their cost of research business so that we can use funds provided in the most effective way to implementation. Universities should share their commitments to the troops and veterans and not make a profit off the endeavor. We can do this in weapon development with tiger teams approaches and filled instruments of war in record time. Can we do the same to save our troops and veterans? Will you have faith in us that veterans and those civilians as doctors, researchers, and members of the Veterans Affairs Research Advisory Committee that have committed to help. Will you put the full weight of this government and it's resources to this task? Our remaining lives and qualities of our lives depend upon you.

Thank you very much for the honor to appear before you today. I would be delighted to answer any questions you may have.

[The prepared statement of Ms. Nichols appears on p. 47.]

Mr. HARE. Thank you Ms. Nichols. Thank you very much for your service to this Nation and for all the work that you are doing now.

I just want to say one thing before I ask a couple questions of the panel. General, one of my closest friends was a retired Catholic priest and I can remember to this day he would say, "Phil, we hear about faith, hope, and love, the greatest being love." But he said, "If you take hope away from people for them getting up every day and to try to do what they can do best." He said, "While we talk so much about love, always remember that hope is, from my perspective, equally important."

And I just want you to know that it is my sincere desire that the HOPE Program that you mentioned, I think it is a wonderful thing. And I think we need to look at it and I think we need to work on it, and I think we need to do it now. I don't think—every hour that goes by is time wasted. And so, I just wanted you to know that your testimony was very compelling and I am just incredibly honored to be Chairing this hearing this morning with such wonderful panelist.

I do want to know, maybe and the whole panel could talk to me, the General talked about a congressionally directed ALS task force and the timelines, and establishing it in a 30 and 60, 90-day time line that you suggested, General. Could you all tell me what, in your opinion, would you suggest would be the top three goals of that task force.

Brigadier General MIKOLAJCIK. I'm sorry. The——

Mr. HARE. The task force that you were proposing.

Brigadier General MIKOLAJCIK. The top three goals of the task force would be, number one, determine what agency in government would take the leadership role. Number two, develop a strategic plan to be followed. Number three, provide adequate funding to support that strategic plan.

Mr. HARE. Mr. Hardie. Ms. Nichols?

Mr. HARDIE. I would certainly concur with those comments. I think that is an excellent action plan.

Mr. HARE. Okay.

Ms. NICHOLS. Very definitely a definite goal timeline to meet.

Mr. HARE. Okay. Mr. Hardie, in your testimony you stated that being seen is not the same as being treated. And I would like, if you could maybe go into it a little bit more regarding that statement. And then you also said that many Gulf War veterans have given up going to the VA. Do you know if they are going elsewhere or they are just not going anywhere at all?

Mr. HARDIE. Thank you, Mr. Chairman. In terms of not being seen is not the same as being treated. VA continues to have an open door and it is always possible to get appointments with general medicine practitioners. In terms of being seen by specialists, if it appears that there is some sort of a condition as well, I think that Gulf War veterans are able to be referred to specialty care as well. But again given the lack of an understanding of the underlying mechanisms causing Gulf War veterans illnesses, my sense is that many treatment providers really don't know what to do with Gulf War veterans.

I had, for myself, I have had significant immune dysfunction growing over the last several years. I had an absolutely brilliant immunologist tell me, "I am simply not smart enough to know what to do with you. Here are some suggestions for where to go."

And so, I continually—my experience has been being seen by, by the way that was not a VA practitioner. I did seek outside care after having been shuffled around for quite some time.

In terms of Gulf War veterans going whether they are going elsewhere or simply stopping getting care, my sense is that those are some veterans are—some Gulf War veterans are continuing to seek care at the VA, but again and elsewhere but after a time it seems that many of the people that I am in contact—many of the Gulf War veterans that I am in contact with have simply given up on, until there is some new breakthrough, there is no point in going back and being told, "We don't know what to do with you. We see your symptoms. We can certainly give you limited prescriptions to treat some of the symptoms that you are experiencing. But in terms of what is causing these kinds of things, we don't know." And until there is, we simply don't know.

I would hope that gives a sense of the answer to those questions.

Mr. HARE. Yeah. Just real quickly, because I am running out of time. Mr. Hardie, outreach can be a great tool and sharing it with the veterans from past wars so they are kept informed of any changes or developments that may occur. It has been 16 years since the Gulf War I ended. Just a couple quick questions.

Do you think the outreach efforts of the VA have diminished in these 16 years? If so, how? My second follow-up would be what changes do we need to do to affect that outreach?

That would be for Ms. Nichols, if I could.

Ms. NICHOLS. Okay. On the point paper I have provided this morning for you, I went step by step, there is 23 steps there. But the outreach needs to be very extensive. I think we need to bring in outside experts in the anti-aging area that is a board certified field medicine that can help from the top down.

I think a lot of the things that are covered at the VA Research Advisory Committee meeting, the updates on research, there is excellent material there. I have encouraged to be videotaped, get out there on the web, get out there the physicians in the VA hospital and to the patients, the veterans. I have encouraged that from day one and it hasn't been done. That is a simple thing that could be put in place to you know further the outreach and education of all involved, not only the patients but the physicians that are to care for us at the VA.

But I think we need some other experts put on contract to come in and do some education also on other things that are available in the civilian world that could help. A lot of it connects with chronic fatigue and there is a lot of breaking research in that area.

Mr. HARE. Thank you, Ms. Nichols. Mr. Brown?

Mr. BROWN OF SOUTH CAROLINA. Thank you, Mr. Chairman and I really thank the other Members of the panel for coming too. I know I made my introduction to General Mik, but I am glad to have you all here.

And General Mik, my first question is to you is, how were you diagnosed with ALS and how long did it take for you to be granted your VA benefits?

Brigadier General MIKOLAJCIK. Thank you for asking that question. And there is no one test that tells you, you have ALS. I was having an annual physical and there were fasciculations that the

doctor saw on my shoulders. That is uncontrollable muscle movement. He asked me how long have I had those fasciculations? I said, "What is a fasciculation?" He said, "Look in the mirror." I looked in the mirror, I said, "I have never seen them." Then I was sent to a neurologist, who did an EMG; did a CAT scan; did other things. And then they said, "You probably have ALS or some other disease."

So through a process of elimination, it wasn't Lyme disease, it wasn't Kennedy's disease, it wasn't benign fasciculations, even though they immediately put me on the one drug, Rilutek, which was used for ALS. It is a guessing game until more parts of your body start to lose functionality or your speech. It took me 2 years before I was granted disability, partial disability by the VA. And it took another 6 months before I was granted full disability.

There is no one scientific test to identify ALS. That is why the research is so important to find those biomarkers that may identify ALS patients whether it be through DNA or whatever, so that you could start treatment sooner. It is not like other diseases, cancer or whatever that there is a test that tells you, you have it. ALS is not that way. Lou Gehrig gave up his order of batting because he couldn't hold those two bats in his hands to practice swinging. After 2,130 consecutive games. He was the iron man of baseball. Most ALS patients are very healthy. I was taking an 80 milligram a day of aspirin when I was told I had ALS. Most ALS patients are very athletic. Why? We got to do the research to find out.

Why do Italian soccer players have a higher incident rate than non-soccer players? We don't know. Why do pilots have a 2.6 times incident rate of ALS compared to non-pilots? We don't know. And the reason, Mr. Chairman, I talked about leadership is I spent 27 years in the Air Force. There was always a leader. There was always direction. There was always cooperation on whatever you were doing. There is no leadership in ALS. Just like these blocks on the table. These are blocks from when I was a child over 50 years ago. Anybody that had ALS then or that has it now is not much different than those blocks. It is a sad state.

So that is why when you ask me what are the three things, number one, has to be leadership. Number two, you have to have a strategic plan on how you are going to go do things. And by having a plan and by having a leadership, you can also save money in research because you do away with a lot of the duplication that is going on. I don't know how many organizations have tested Mynocycline for ALS. We have tested on mice; we have tested on patients; we keep on giving grants out to test Mynocycline. Something is wrong in that equation.

Mr. BROWN OF SOUTH CAROLINA. I notice in your remarks you said that one of the easiest tasks would be to establish and fund a national ALS Registry to ensure comprehensive patient information. You mean we don't have one already?

Brigadier General MIKOLAJCIK. No, there is no national registry. There has been a number of organizations, the ALS Association that have been trying for a number of years. It was voted upon on the House side in one of the conference subcommittee's and it was passed. There is over 50 percent of the Congressmen in this Congress that have signed as sponsors for the bill. I understand that

today the full Congressional Committee is voting on the bill. The Senate, I don't remember where the progress stands on that. But the ALS registry for veterans is so small, part of it is you got to know there is a registry to sign up for the darn thing. If you are not computer literate, if somebody didn't tell you, your name is not on that registry.

So the national registry would put many more people into the database. To find out, have you used pesticides? Have done certain things? Have you had certain medications? And it doesn't cost a lot for that national registry to be formed. So I would encourage this Subcommittee and the Members to support the registry that is being voted upon in this Congress.

Mr. BROWN OF SOUTH CAROLINA. I know my time is expiring, Mr. Chairman. If I might just make one statement. I know that there is, I hope there is some collaboration between the DoD, National Institutes of Health (NIH), and other ALS research funding. I know that in the Defense Bill that the Appropriation Bill coming before us, we requested $4.8 million for an ALS Therapy Development Institute. And this support would support cutting edge first fast track drug discovery and traditional research. We were able to get one and a half million dollars, General. And so we hope this will help. And but that is a shame if we got to make their marks look like, you know, DoD should take this responsibility on their own. But we are pleased to announce that.

Brigadier General MIKOLAJCIK. That sure is. And that is a small amount of money for the task ahead. I visited the ALS Therapy Development Institute a little over a year ago in January. I was visiting my mother in Connecticut. I heard about them. I asked if I could come visit. I wanted to see the mice that were taking the same drugs I was taking. See what they looked liked. What was going on? What is the technology there? And I was overwhelmed by their discipline and their sole focus on ALS. I am a believer in where they are and where they are going as they move forward in that direction.

And there are other laboratories that are doing work. What we don't have is the drug companies are not putting much money into ALS research. Why? What is the return on investment? Bottom line. What is the return on investment? BioGen a very large drug company in the State of Massachusetts about a year or so ago disbanded their whole ALS research center. That is why the government has a responsibility, because private industry won't step up unless you give them some money to do that.

Mr. BROWN OF SOUTH CAROLINA. Well, look, I thank you for your testimony. And I will yield back my time, Mr. Chairman.

Brigadier General MIKOLAJCIK. I would like to make one more comment in relation to that.

Mr. HARE. Absolutely.

Brigadier General MIKOLAJCIK. We all know a lot of patients that have Multiple Sclerosis. The incident rate of Multiple Sclerosis and ALS is not that much different. ALS is somewhere between 5,600 to 6,000 a year. For MS the incident rate is somewhere around 8,000, 8,500 a year. Why are there so many MS patients? It is because MS patients live 20, 30 years. We don't. Our statistics, you

know, the doctor told me, "You have 1 to 3 years to live. Get another opinion. Take Rilutek. Come back and see me in 6 months."

So the numbers are small because there are not many of us and a lot of us can't speak. Thank you, Mr. Chairman.

Mr. HARE. Thank you, General. Mr. Moran?

Mr. MORAN. I thank you, Mr. Chairman. I want to thank you, General, for speaking. I only have a few questions, but I suppose perhaps more important than questions is that all of your testimony is a reminder of the importance of us providing greater leadership, more emphasis, and support for the efforts that you are outlining. And so, I appreciate the opportunity to be here this morning just to remind me that there is a cause that needs champions in Congress and across the country.

So, if, despite the information that you are conveying to me, perhaps more important you are conveying to me the need to go to work. I appreciate all of you providing me with that challenge, that opportunity, and that—a reminder of my responsibilities.

Is ALS, is it unique in it's correlation between military service and incidence as compared to any other condition or disease? Is this a very unique circumstance? A very rare correlation?

Brigadier General MIKOLAJCIK. It is a fact. Why? I don't know. Is it unique for military service?

Mr. MORAN. Is it, compared to any other disease or condition, is——

Brigadier General MIKOLAJCIK. I know of no other disease——

Mr. MORAN [continuing]. Incidence of ALS and its relationship to military service is it very unique?

Brigadier General MIKOLAJCIK. Yes. I know of no cancer that is associated just with military service or other things.

You know I looked through the Defense Bill and there is about a billion dollars in earmarks for different research within in the DoD Bill. The only disease that I saw that had a direct connection to military service was ALS. The rest of them were not. Prostrate cancer, breast cancer or other types of things. It is unique.

Oh, and the Gulf War Syndrome. I am sorry. And the Gulf War Syndrome, ALS is the only named disease within that terminology.

Mr. MORAN. The Gulf War Syndrome is a broader description of a variety of conditions, ALS is a subset of that broader description?

Brigadier General MIKOLAJCIK. Yes. But how do you look at veterans from Somalia, veterans from Haiti, veterans from Bosnia, veterans from Korea, World War II and Vietnam. Why do they have a 60 percent higher incident rate?

Mr. MORAN. Is that incident rate, that correlation, is it the similar percentage regardless of location of service? Whether you were in Somalia or you were in Iraq or Afghanistan, same statistical relationship?

Brigadier General MIKOLAJCIK. We don't know the answer.

Mr. MORAN. Okay. Again, it goes back perhaps to the registry, the facts?

Brigadier General MIKOLAJCIK. Right.

Mr. MORAN. Okay.

Brigadier General MIKOLAJCIK. To gather that data to run the test, to do the DNAs, to spend more on specific research for ALS. I am disappointed in some of the government's research just on ex-

posure and toxins. Because when you look across the broad spectrum it is not just exposures or toxins that probably trigger the disease in it. We may all have it and something triggers it. What it is, we don't know. But to narrowly focus on exposures and toxins to me is delaying the time in which we will find a therapy or a cure.

That is why a multi disciplinary approach with leadership is what we need.

Mr. MORAN. General, thank you for your testimony. Mr. Hardie and Ms. Nichols, thank you very much for your advocacy.

Mr. HARE. Let me again thank the panel for coming this morning and thank you for your service to this Nation. I just want to let you know that from my perspective I will do everything I can, General, to help on this. I think it is way overdue.

And, finally, Ms. Nichols you asked a series of questions in your testimony and yes to all of the ones you asked. So thank you very much for coming this morning.

Brigadier General MIKOLAJCIK. Mr. Chairman, I would like to make one more comment——

Mr. HARE. Sure.

Brigadier General MIKOLAJCIK [continuing]. If I may, please? I would like to thank Congressman Brown from the first congressional district of South Carolina, for all that he does for the veterans not only of South Carolina, but also of our country. I personally want to thank him for supporting me over these years as we have gone through this struggle to set up an ALS Chapter in our State, to make a loan closet, to have an ALS clinic. And I am deeply indebted to you, Congressman Brown, thank you very much.

Mr. HARE. Thank you, General. And thank the panel.

This panel is excused. And thank you again, General, for taking the time to be with us.

We welcome our second panel. I would like to introduce at this time, Dr. Meryl Nass from Mount Desert Island Hospital who has treated Gulf War veterans; James Binns the Chairman of the Research Advisory Committee on Gulf War Veterans' Illnesses; and Dr. Lea Steele, Scientific Director for the Research Advisory Committee on Gulf War Veterans' Illnesses. I got all that right. Not too bad for a rookie here.

So I thank the second panel and, Dr. Nass, we will begin with you.

STATEMENTS OF MERYL NASS, M.D., INTERNIST AND HOSPITALIST, MOUNT DESERT ISLAND HOSPITAL, BAR HARBOR, ME; JAMES BINNS, CHAIRMAN, RESEARCH ADVISORY COMMITTEE ON GULF WAR VETERANS' ILLNESSES, U.S. DEPARTMENT OF VETERANS AFFAIRS; AND LEA STEELE, PH.D., SCIENTIFIC DIRECTOR, RESEARCH ADVISORY COMMITTEE ON GULF WAR VETERANS' ILLNESSES, U.S. DEPARTMENT OF VETERANS AFFAIRS, AND ASSOCIATE PROFESSOR, KANSAS STATE UNIVERSITY

STATEMENT OF MERYL NASS, M.D.

Dr. NASS. Thank you very much for holding this hearing. I practice internal medicine in Maine. I have a background in Anthrax

and biological warfare and conduct a specialty clinic for patients with multi-symptom syndromes, including Gulf War Syndrome, Anthrax vaccine-induced illnesses, fibromyalgia, and chronic fatigue syndrome.

The stories of those with Gulf War or Anthrax vaccine-induced illnesses are usually heartrending. Most became disabled in their twenties to forties with a combination of physical impairments, cognitive problems, and psychiatric disorders. They carry 10 to 15 diagnoses each on average. Five patients gave me permission to share their medical records with this Committee if you wish to see them.

My care for more and more of these individuals has compelled me to continue to research and write about their plight, to try to prevent further "friendly fire" injuries and to address the barriers to good care for the injured. I want to tell you four things today.

First, Anthrax vaccine can cause a wide range of disorders, but most commonly causes a syndrome clinically indistinguishable from Gulf War Syndrome. Many studies have shown that it was a contributor, but certainly not the only contributor, to Gulf War illnesses. Data from the military's Defense Medical Surveillance System have shown that vaccinated servicemembers have significantly elevated rates of heart attacks, several cancers, asthma, diabetes, Crohn's disease, psychoses, depression, and blood clots, compared to pre-vaccination rates.

A U.S. government Accountability Office (GAO) report last month cited the Centers for Disease Control and Prevention (CDC) and Military Vaccine Healthcare Center officials saying that one to 2 percent of Anthrax vaccine recipients may experience potentially disabling side effects or death. The Assistant Secretary of Defense for Health Affairs concurred with this report. I would like to refer you to my written testimony for the details and sources; I am going to talk broadly in this verbal testimony.

Second item, DoD and Department of Veterans Affairs funded a huge portfolio of research that was carefully designed to create a smoke screen around both Gulf War illnesses and Anthrax vaccine injuries, presumably to deflect culpability from government decisions and actions that led to the massive collateral damage caused to Gulf War veterans and Anthrax vaccine recipients. The result is confusion in the minds of patients, medical practitioners, and policy makers. Last week, a patient of mine and his wife cried in gratitude in my office when I told him he had Gulf War syndrome and not a psychiatric illness, even though I said it could not be cured. His VA doctor, he said, didn't believe in Gulf War illnesses. That should not be happening today, and it is largely a consequence of the failed body of Gulf War research.

The VA and DoD-funded research has been successful at delaying the provision of pensions and appropriate care for affected veterans, and taking away their self respect.

Third item. This situation does not need to continue. Both the research, treatment and disability assessment for veterans can be improved and made fair.

Fourth. Troops would not so easily be placed in harm's way if the Department of Defense bore the long term costs of their injuries. DoD continues to expose soldiers to a range of potentially debili-

tating exposures, such as aerosolized depleted uranium, illegal levels of toxins on military bases, and known dangerous vaccines for which no threat has been demonstrated and for which safer approaches exist.

Ill soldiers are medically discharged and the cost of their future care shifted to the VA. If Congress made sure that some of these costs were borne by the Pentagon, it is certain the long-term health of soldiers would be taken more seriously.

What should be done? In terms of research, a total of seven Federal advisory groups and the Committee on government Reform have made detailed recommendations for the types of long term studies that should be done on Anthrax vaccine. Their recommendations should be carried out. These groups include three Institute of Medicine Committees, the Advisory Committee on Immunization Practices of CDC, VA's Research Advisory Committee, the Armed Forces Epidemiology Board, and the GAO.

The CDC has been conducting a trial of Anthrax vaccine in 1,500 civilians since 2002. Over 100 adverse event reports have been filed with FDA on trial subjects, but no preliminary data have been released to the public and the investigators have decided to focus on short-term adverse events.

Congress could investigate this study and insist that adequate long-term safety data are collected. Studies like this have the ability to tell us once and for all the precise side affect profile of this vaccine and the rates of adverse reactions.

What should not be done? History should cease repeating itself. In 1997, Phil Shenon of the New York Times reported on Congressman Shays' investigation of Gulf War illness research. He said, "The Pentagon and Department of Veterans Affairs have so mishandled the investigation of the veterans' health problems that Congress should create or designate an agency independent of them to coordinate research into the cause of the ailments."

Now it is 10 years and $260 million later and absolutely nothing has changed.

Failed research does not happen by itself. In the case of Gulf War and Anthrax vaccine studies, a number of issues can be identified that led to unusable results: the wrong questions were asked; data was withheld; dubious methods were chosen; sample sizes were inadequate to answer the questions asked; control groups contained exposed subjects; and exposed groups contained unexposed subjects.

Those government officials who deliberately wasted hundreds of millions of dollars on a wild goose chase should be subject to charges of research misconduct. Congress can pass a law to establish criteria and penalties for such conduct, similar to existing NIH regulations.

The officials responsible for this research charade could be barred from future government grants and contracts and future government employment. A new Federal agency should be created with a responsibility for only drug and vaccine safety. Currently, agencies responsible for promoting drugs and vaccines are also responsible for safety, and this inherent conflict of interest has resulted in repeated failures to regulate appropriately. A bill like this

was introduced in the last Congress, I believe by Representatives Carolyn Maloney and Dave Weldon.

Finally, government officials who supported and expanded Anthrax vaccinations while in office are now on the payroll of the vaccine manufacturer or companies with government contracts related to Anthrax vaccine. This includes two former U.S. Department of Health and Human Services (HHS0 secretaries. Congress should pass a law to prevent such egregious conflicts of interest in future.

In conclusion, we know Anthrax vaccine and other toxic exposures are dangerous to susceptible individuals. Clear steps can be taken to reduce future injuries, treat the injuries that exist and achieve accountability for the deliberate failures that have occurred. Thank you very much.

[The prepared statement of Dr. Nass appears on p. 51.]

Mr. HARE. Thank you. Mr. Binns?

STATEMENT OF JAMES BINNS

Mr. BINNS. Mr. Chairman, Members of the Subcommittee, it has been my privilege to Chair the Research Advisory Committee on Gulf War veterans illnesses. This public body of distinguished scientists and veterans is mandated by Congress and appointed by the Secretary of Veterans Affairs. Dr. Steele to my left is a member and Scientific Director of the Committee. She will provide highlights of the Committee's cientific findings, I will address the status of Federal research programs.

Gulf War illnesses remain a major, unmet veterans health problem. According to the Department of Veterans Affairs most recent study, 25 percent of Gulf War veterans suffer from chronic multisymptom illness above the rate in other veterans of the same era. This confirms five earlier studies showing similar rates. Thus, 16 years after the war, one in four of those who served 175,000 veterans remain seriously ill. There are currently no effective treatments.

Gulf War veterans also suffer from ALS, as you have heard, at double the rate of other veterans of the same era. That is double the rate of people in the military which we have already heard is in excess of the normal background level in society.

The Federal Government has spent over $300 million in Gulf War illness research. Much of that money, however, was spent on the false theory that these illnesses were caused by psychological stress. Part of an overall effort to portray these illnesses as nothing unusual, the kind of thing that happens after every war rather than the result of toxic exposures.

Very little money was invested in treatment research. I am pleased to report that a major change for the better has recently taken place in the direction of VA research. Following our Committee's 2004, report then Secretary Principi determined that VA would no longer fund research based on stress. Secretary Nicholson appointed new leadership at the Office of Research and Development and placed most of VA's research program at the University of Texas Southwestern Medical Center, a leading site for Gulf War illnesses research.

I am pleased to see VA Gulf War illness research in the hands of scientists committed to solving the problem and funded at the

$15 million level recommended by the Research Advisory Committee. I regret that I must also inform you, however, that other VA officials continue to minimize these illnesses. For example, a fact sheet provided in recent weeks to three U.S. Senators asserted, "Gulf War veterans suffer from a wide-range of common illnesses which might be expected in any group of veterans their age."

That is utter hogwash. This fact sheet is the work of the VA Office of Public Health and Environmental Hazards, which is testifying before you today. It is also the office charged with implementing the law requiring VA to contract with the Institute of Medicine for reports on the health affects of toxic exposures for use and benefits determinations. For 7 years, these reports have been structured to restrict the scientific information considered in their conclusions in express violation of the statute, misleading the Secretary, Congress, doctors, and medical researchers.

Dr. Lawrence Deyton who directs this office and will speak to you later this morning assumed his position relatively recently and did not initiate these practices. I urge this Subcommittee and Dr. Deyton to order these misleading and unlawful activities terminated. While VA Gulf War illness research is adequately funded at last, two-thirds of Gulf War illnesses research has historically been sponsored by the Department of Defense. Over $30 million annually. Since the start of the current war, however, this research program has been eliminated. As a result, the total Federal program is at one-third strength.

Last year Congress initiated an innovative new pilot program at DoD focused on studies of treatments already approved for other illnesses. It is open to all researchers on a competitive basis. It's initial solicitation last fall attracted 80 proposals compared to only two treatments studied in the entire previous history of Gulf War illness research. Yet, DoD has again excluded this promising program from it's proposed fiscal year 2008 budget. It's future depends entirely on Congress.

Mr. Chairman and Members of the Subcommittee, in recent months this country has renewed it's obligation to care for the health of veterans that return home from war. Hundreds of millions of dollars have been appropriated to address the problems of currently returning veterans and rightfully so. But it is now time, in fact long past time, to address the health problems of 175,000 ill veterans of the last war.

Will we follow the example of the current war and address them now while there is still hope they can live out their lives in better health? Or will we follow the example of Vietnam and agent orange and admit the problem only as they are dying? The answer begins with you and your colleagues.

[The prepared statement of Mr. Binns appears on p. 57.]

Mr. HARE. Thank you, Mr. Binns. Dr. Steele?

STATEMENT OF LEA STEELE, PH.D.

Dr. STEELE. Good morning. I am Dr. Lea Steele. I am an epidemiologist and a professor at Kansas State University. And I have been involved in research on Gulf War veterans for almost exactly 10 years when 10 years ago my home State of Kansas stepped up to the plate and sponsored a research and service program for Gulf

War veterans in Kansas. And we much appreciated the interest and support of Congressman Moran for that program over the years.

But now at this time, I am privileged to serve as the scientific director for the Research Advisory Committee on Gulf War veterans illnesses. As Mr. Binns said, this is an auspicious group of scientists and veterans who are dedicated to addressing these problems. We have now reviewed thousands of scientific studies, government reports, special investigations, special Committee reports, all related to what happened during the Gulf War and the health consequences for Gulf War veterans.

My purpose today is to just give you the highlights of some of what we have learned in the course of our scientific work. But I wanted to let you know that later this year we will be issuing a major comprehensive report that contains our scientific findings and recommendations based on this extensive information. And I think you will find that report to be of great interest.

Let me just first start by distinguishing a couple of the items that have been raised already today. First, most of my comments will focus on what we are calling Gulf War illness. This is what was previously called Gulf War Syndrome. This is the undiagnosed multi-symptom illness that has been described by veterans and several of our speakers this morning. I want to distinguish that from the diagnosed conditions that also affect Gulf War veterans. These include ALS, a very serious condition. And as Mr. Binns has said, we know that it affects Gulf War veterans at twice the rate of other military veterans. So as new information becomes available saying that all military personnel from whatever era or whether they deployed or not, if all military personnel have higher rate of ALS then the general population, the fact that Gulf War veterans have twice as high a rate as other veterans remains a particular concern in relation to Gulf War service.

There are other diagnosed conditions that have been raised as possibly affecting Gulf War veterans. One recent one is brain cancer. I think many of you are familiar with one incident that happened just after the cease fire in the Gulf War in which the Pentagon has estimated that 100,000 Gulf War veterans were potentially exposed to nerve agents, sarin and cyclosarin. We have only known since 2005 that those veterans have died from brain cancer at twice the rate of veterans who were not in that area.

So that is another diagnosed condition. But again I want to distinguish these important issues and very serious issues from Gulf War illness. And that is because, although these are serious medical conditions, they have affected relatively few veterans of the Gulf War in contrast to the alarming numbers of Gulf War veterans who have been affected by Gulf War illness.

And I think you all have a pretty good idea of what Gulf War illness looks like. Multiple symptoms in multiple body systems that occur all at the same time and can be quite debilitating; severe headaches, memory problems, concentration problems, dizziness, fatigue, pain throughout the body, gastrointestinal problems. We know many veterans have had diarrhea for 16 years. This is very serious and can be quite debilitating for affected veterans.

So it is not what we see in the general population and it is not what we see in any veterans group of similar age. Luckily, as I said, a lot of research has been done on this condition. We now have some answers and know some things about Gulf War illness. We have a pretty good idea of how many veterans are sick. We have a pretty good idea of who is most affected and we also have strong evidence regarding what may have caused this condition. And again, I will just share with you some of the highlights.

First, as we have heard earlier today, Gulf War illness is a big problem. That is 25 to 30 percent have been shown in study after study to be affected by this multi symptom condition. As Mr. Binns said that translates to between 175,000 Gulf War veterans and 200,000 Gulf War veterans.

Second, I want to be very clear about this. The evidence clearly indicates that Gulf War illness was not caused by psychological stress. We now have many, many studies that have looked at psychiatric illness and psychological stress in the Gulf War. No comprehensive well-conducted studies have found any connection between combat stress and Gulf War illness.

In addition, rates of psychiatric conditions like post traumatic stress disorder are much lower in Gulf War veterans than in veterans of any other war that we have looked at. And this stands to reason. As Mr. Hardie said the war was over in a matter of days, the ground fighting, and the whole war was over in 6 weeks. Most Gulf War veterans did not engage in combat and were not even in areas of theater in which combat took place. So Gulf War illness is not a stress condition.

The next major point is that if stress didn't cause Gulf War illness, what did? Well we know there are a lot of potential candidates and we have heard about some of them this morning. Burning Kuwaiti oil wells, numerous military vaccines, depleted uranium munitions, low-dose exposure to chemical weapons. What I can tell you is that the most consistent evidence and the strongest evidence points to a group of chemicals that we know can have toxic affects on the brain. This group of chemicals includes a little white pill that personnel were given to protect them from the affects of nerve gas. They took this pill around the clock in the event of exposure to nerve gas. The second neurotoxin we are concerned about relates to the massive and wide spread use of many different kinds of pesticides during the war. And the third neurotoxin that we are concerned about are the low-level exposures to nerve agents.

What you may not know is that this group of chemicals actually have similar affects on the brain and many of them affect one specific brain chemical, acetylcholine. This is also compatible with what we know about the biology of Gulf War illness. That is we now have multiple studies showing brain damage and reduced brain function in sick Gulf War veterans. These have been covered in the media recently showing that veterans with reduced brain function also have reduced volume in specific areas of their brains.

So, again, we are very concerned about this, but it is useful to note that this large body of evidence all sort of converges on the central point of neurotoxins. Now my last very important point has been raised before by veterans who are ill and by Mr. Binns. And

that is there are no effective treatments for Gulf War illness. We now have four studies that have followed up the health of Gulf War veterans over time and they all tell us the same thing. And that is very few Gulf War veterans with Gulf War illness have recovered over time and very few have even substantially improved over time. So as a result we have many, many veterans with Gulf War illness that have been sick for as long as 16 years.

Our Committee has long considered treatment research to have the highest priority of all research related to Gulf War veterans.

So in short, I will just summarize by saying that Gulf War illness is real. It is serious. And it is still widespread among veterans of the 1991 Gulf War. It is not the result of psychological stress and it is certainly not the same thing that happens after every war.

We have seen some progress in understanding the big picture questions about Gulf War illness and our Committee believes that remaining important questions can be answered and must be answered. And this is of course because the government has an obligation to take care of veterans who are chronically ill now as a result of their military service, but it also because we want to be sure that by more completely understanding Gulf War illness we can prevent anything like this from happening in future deployments. Thank you.

[The prepared statement of Dr. Steele appears on p. 59.]

Mr. HARE. Thank you all very much for coming and testifying this morning. I have a question of the panel and then maybe a couple for you, Dr. Nass.

The General proposed in his testimony that a Congressionally directed ALS Task Force be established. And I just wanted to know from the panels' perspective your thoughts on creating another task force or entity to look into ALS, and if you believe the direction the VA is taking with ALS is the correct way?

Mr. BINNS. Let me comment on the aspects of the question that I can address. First of all, I am not a scientist. My background is in business in developing medical equipment. Specifically, if you have had an ultrasound scan that is the kind of equipment that the companies that I was involved in starting and building developed.

The General is absolutely on target when he points to the blocks and says that this is the kind of disjointed effort that is produced by government and university research in general. It is not just true in ALS, it has been true with what I have seen in Gulf War illness.

So a comprehensive and coordinated program such as he suggests is an excellent idea. And it is one that only people I would say who have been outside of this what I would call government academic complex with due apologies to my colleagues here can understand. Unless you have been in the military or you have been in the private sector, somehow it is not just answering interesting questions that we are about here. It is trying to achieve a goal. And the programs as they are conducted, and this is not through any malice necessarily at all, but just because of the nature of them don't accomplish that.

I am not familiar with the details of the Federal—the VA Gulf—ALS program, so I can't comment on that.

Mr. HARE. Thank you.

Dr. NASS. I would just agree with everything Mr. Binns has said.

Dr. STEELE. I as well.

Mr. HARE. Thank you.

One more question for the panel. We have had 16 years that have passed and the veterans of the Gulf War are still fighting to be recognized and not forgotten.

What would your recommendations be on how to effectively improve Gulf War illness research, outreach, education, and treatment?

Dr. STEELE. Well, you have our 2004 report and we gave very specific recommendations about the research arm of what you are asking about.

Mr. HARE. Thank you.

Dr. STEELE. Our next report will also give detailed recommendations. But part of the issue was, as the General and Mr. Binns raised, just having a comprehensive and well-planned program to actually solve the problem instead of study little pieces of it around the periphery. That is a major issue.

The other issue has to do with funding, of course. We have seen so many dollars spent on Gulf War illness research over the years. But as you have heard, a lot of it has gone down the wrong alley.

And now that we are finally beginning to understand Gulf War illness, it is really the time to put some more dollars behind it, but put it in the right hands and put it into a program that has managed to achieve results.

Mr. BINNS. Let me take a——

Mr. HARE. Sure.

Mr. BINNS [continuing]. Chapter from the—another chapter from the General's message and offer you an answer and not just a problem.

We now have, I think, a very good start on a comprehensive Federal program. As I mentioned, VA has $15 million which is what the Research Advisory Committee has recommendation committed to this effort. And they have placed most of it in the hands of researchers at the University of Texas Southwestern who believe in the problem.

We now need to make sure that they do their job and develop a comprehensive program. Their program is oriented toward treatments. But in the long haul, that is the conventional medical approach, scientific approach of understanding the basic science, targeting what the underlying mechanisms are, and ultimately identifying or developing treatments to address that mechanism.

At the same time, thanks to Congress, not to the Department of Defense, in 2006, a pilot program was started at DoD which is looking at what you might consider the quick, less likely, but quicker approach to developing treatments which is to see if you have a treatment already on the books, on the shelf that could work for this application.

And I am not suggesting you try treatments willy nilly, but there are logical ways of approaching treatments to detect which ones are promising and studying them.

As I mentioned, with this Congressionally managed proposal put out, they received 80 proposals from researchers around the coun-

try and some of them from other countries suggesting treatments and diagnostic tests that could be tried.

So this program unlike many of the programs in the past has a strategy that is promising and works. All that is needed now is to fund it to balance the program that VA is funding at the University of Texas.

The problem is this is actually the bigger piece. DoD has funded two-thirds of research in the past and they are not funding anything as of this minute.

So if you want to have a comprehensive program, you have the makings of it. You just need to fund the $30 million in the DoD budget to balance the $15 million in the VA budget and you will have a very coordinated program.

Mr. HARE. Thank you, Mr. Binns. My time is out, but I would like to, on my second round, Doctor, ask just a couple brief questions. So, Mr. Brown?

Mr. BROWN OF SOUTH CAROLINA. Thank you very much for your testimony. And if I might address this to Dr. Steele or anybody can include in, but apparently one time, you worked with the University of Kansas?

Dr. STEELE. Kansas State University.

Mr. BROWN OF SOUTH CAROLINA. Kansas State. Okay.

Dr. STEELE. I still do.

Mr. BROWN OF SOUTH CAROLINA. Okay. And, Dr. Binns, you mentioned about Texas, a research program there. And I guess that was one of the things that the General alluded to, that apparently there is diverse testing around the country and who has the umbrella to kind of digest all the results of these tests.

And I was alarmed to find that in all the research, there is not a data bank that monitors, you know, all the folks that are involved with ALS. And I know that you all are addressing other diseases besides ALS. But what can we do to kind of bring some kind of oversight to the process so we can have, you know, one path that everybody is traveling?

Dr. STEELE. Are you asking me or Mr. Binns? Actually——

Mr. BROWN OF SOUTH CAROLINA. It was directed to you primarily.

Dr. STEELE. Thank you.

One of the charges to our Committee is to provide this oversight of all the research related specifically to the health of Gulf War veterans. The question about ALS, I believe there is no such oversight Committee.

So we are in the position to monitor all of the research related to the health of Gulf War veterans including ALS and Gulf War illness.

Mr. BROWN OF SOUTH CAROLINA. I did not mean to interrupt, but you are focusing—ALS is one of the Gulf War components, right?

Dr. STEELE. Yes. That is one of the diseases affecting Gulf War veterans, correct.

Mr. BINNS. Let me distinguish, though, between what we are charged to do and able to do and with what, I think, you are asking about, sir.

We are advisors. Dr. Steele has a staff of two other people to look at a very large body of research and we can prepare reports suggesting areas to look at. We conduct public hearings and so forth.

What is necessary to achieve the goal you are speaking about, whether it be for Gulf War illness research or for ALS research, is a larger body of scientists who are focused on doing that role full time and nothing else, who are not conducting necessarily their own studies, but who are assimilating and directing the studies of others. Nobody does that in medicine today except for a very handful of people in private organizations. And NIH may do this. I can say with respect to Gulf War illness, nobody does it.

Mr. BROWN OF SOUTH CAROLINA. Yes. That would be my leading question is, are you all applying for NIH grants to try to further your research? Is that one of the money sources or you just go to the VA and the DoD?

Dr. STEELE. We serve on the Advisory Committee and we do not do research ourselves in that capacity. I can tell you that other researchers cannot apply to NIH for research funding for Gulf War illness research. ALS researchers can apply to NIH in some circumstances.

Gulf War illness research is handled exclusively by the Department of Veterans Affairs and the Department of Defense. And as you just heard, Department of Defense has not funded any this year and the Department of Veterans Affairs only funds researchers that are working at the Department of Veterans Affairs.

So as a result, there are no widely available funds to do research on Gulf War-related health problems.

Mr. BROWN OF SOUTH CAROLINA. I think you were here when I made mention that we were able to get a million and a half dollars earmarked for ALS, you know, Therapy Development Institute and we asked for really four and a half million.

So we did that through an earmark, not from the DoD recommendations. So I guess we could continue to try to support the program through additional earmarks if enough Members, you know, were involved in that process.

But we are looking for some kind of direction that we can move forward. I know that ALS has been around predominantly for 70 years and the Gulf War has been around 17 years. And I know there is a lot of fragmented research out there.

We are just looking for some way that we can get focused, you know, just in one war. That is what we keep talking about one war force, right? That is what we talk about in the military now, one force.

So this is kind of what we are looking for here. If you all could kind of give us some direction, we would appreciate it.

Dr. STEELE. It is a very important issue. Unfortunately, the two realms of ALS research and Gulf War illness research are separate, but we do have specific recommendations for providing funding for Gulf War illness research programs.

Mr. HARE. Mr. Moran.

Mr. MORAN. Chairman Hare, thank you very much.

First of all, I would comment to Mr. Brown that there is a difference between Kansas University and Kansas State University.

Dr. STEELE. There certainly is.

Mr. MORAN. I will not take sides as to who is the leading institution in Kansas, but they are different.

Mr. BROWN OF SOUTH CAROLINA. Kansas City.

Mr. MORAN. Very good.

Let me say that we heard lots of compelling testimony, but the testimony of Mr. Binns, you indicated in your written as well as oral testimony, "this government manipulation of science and violation of law to devalue the health problems of ill veterans is something I would not have believed possible in the United States of America until I took this job."

That is a very strong statement. It is very disturbing to me. I have little doubt but that it is true, and I am confused as to why that would be the case. Why is not everyone's motivation here to find the right answers, cause and effect, and to pursue a cure or treatment of the conditions that our veterans find themselves in.

What is the systematic circumstances we find ourselves in in which you believe that people systematically are trying to avoid accurate information?

Mr. BINNS. You have asked the $64,000 question, Congressman. I do not know the answer. I can speculate, but I think you could get better answers under oath perhaps from the people who followed those policies over the last 15 years.

Obviously you can speculate that it has to do with either—there is a whole long list, but I have no facts to back up what they might be.

Mr. MORAN. I always assume in life that people's motivations are honorable and I would certainly think that is the case when it comes to the care and treatment for men and women who have served this country.

I can guess what people's motivation is, spending of money, the priorities, budget, but just on balance, I cannot fathom why we would ever take the position that we are trying to find a lack of cause and effect. I mean, we ought to have scientific research based upon science, on a neutral initial position.

I suppose I would argue that if there is a bias to be had, it would be in favor, if there is uncertainty, that we as policy makers, not those as scientists, ought to be making decisions based upon the bias toward our veterans. Science ought to be providing us with the evidence, the accurate evidence so that we can make intelligent decisions.

Mr. BINNS. If I may just comment further, I think the attitude on this goes in waves and I think that in the post Vietnam era, there was clearly an attitude on the part of many who were managing Federal policy in this area that was also oriented toward denying and delaying and minimizing this problem. It took over 20 years for Agent Orange to be acknowledged as a problem. Now we know it was a very serious problem.

I think that part of what happened in the Gulf War is that the same philosophy, perhaps some of the same individuals were involved in the government at that time. Just in the last 6 months, there has been a renewal of the commitment of the country brought about, I think initially, by newspaper reporting, but certainly by the attitude of Congress, which I am sure will be reflected in the Federal bureaucracy as that message gets delivered to them.

But I know that for the last—well, even this Committee has held hearings in the past, it has been, I think, more than 5 years because I have been Chairman of this Committee for more than 5 years and I was delighted to get called here.

So the interest in veterans' health begins at Congress. We have seen everything that has happened that I described that is good has been because Congress is interested.

Mr. MORAN. The last hearing that either the full Committee or this Subcommittee had in regard to Gulf War illnesses was in 2002.

Dr. Nass, you seem to want to respond to my comments.

Dr. NASS. Thank you. Yes.

I actually made a memorandum written by Mr. Ross Perot available to Chairman Michaud. I cannot tell you where the initial impetus comes to misdirect research and minimize benefits for veterans.

But what I can tell you is that a small group of people were promoted and were switched around between VA, DoD, CDC, but that this same group has managed to push the theory that stress was the cause of Gulf War illness and to minimize it. And Perot named names and talked about a meeting that was held in which these people were given the order that the cause of Gulf War Syndrome that you are to promote is going to be stress.

Mr. MORAN. Dr. Steele indicated that the scientific evidence of that conclusion is clear and it is not stress related. I believe that is what you are telling us.

Does the attitude that it is stress related still prevail within DoD or the VA?

Dr. NASS. There is a lot of confusion. As I said, a VA doctor told the patient who met the CDC criteria for Gulf War Syndrome that she did not believe it existed.

There continue to be articles published in the literature, repeatedly, by people who have been funded by VA and DoD which minimize, obfuscate. These articles claim we are seeing the same diseases we saw after every war. Yet the fact that 25 percent of Gulf War veterans remain chronically ill is unprecedented. Such articles are just designed to confuse the issue.

Mr. MORAN. I guess Mr. Binns has testified as to that attitude still prevails. It is just a normal occurrence?

Mr. Chairman, I know my time is expired.

Let me ask if there is any different attitude between the VA and the DoD? Is this a monolific circumstance or there is a different approach depending upon whether you are at DoD or VA?

Mr. BINNS. There is a different approach within VA. The VA Office of Research and Development has changed its attitude, but the Office of Environmental Hazards has not.

Dr. STEELE. And it is also not the same top down. Some people within DoD understand the science and some have really not looked into it and perhaps still minimize these problems.

Mr. MORAN. Dr. Steele, thank you for joining us today. As a fellow Kansan, I appreciate your efforts in our home State.

Dr. STEELE. Thank you.

Mr. MORAN. Thank you, Mr. Chairman.

Mr. HARE. Thank you, Mr. Moran.

Dr. Nass, I just have a couple quick questions for you that I wanted to ask before. You acknowledge the symptoms of Gulf War are not unique and that they relate closely with other diseases, conditions, and syndromes.

Just a two-part question here. Could you describe the health effects, if there is a typical case—I do not mean to say that every case is the same—but a typical case of Gulf War illness and how do you treat a patient that is suffering from Gulf War illness?

Dr. NASS. Yes. The typical case meets the CDC definition which is they have a widespread pain syndrome, pain amplification. They hurt in odd places. You cannot find tissue damage and if they do have tissue damage, you know, if they have an injury, they hurt ten times more than a normal person would.

They have cognitive problems which have been documented in repeated neuropsychological studies. They have problems with memory, focus, attention, concentration. They frequently have psychiatric problems.

The patients I see tend to have labile affects. They cry easily. They are easily upset. They are not able to control themselves in public the way most of us can.

In addition, very frequently, they have chronic diarrhea. They frequently have chronic respiratory problems. And then there are a range of—they are fatigued. Almost all of them are fatigued. They are stiff.

Some of them have frank musculoskeletal disease so that the Vaccine Healthcare Center came up with a case definition of an Anthrax vaccine-associated muscle disorder, in which muscle enzymes were elevated and the muscle did not function well and people hurt.

The Vaccine Healthcare Center doctors worked with CDC, but somehow they never published a case definition. And when I asked one of the doctors at CDC who is responsible for some of this type of research, he tried to tell me that CDC was completely uninvolved with it. So they wanted to bury this. They did not want anyone to know that these exposures actually may cause some new illnesses.

In addition, as Lea said, I agree with everything Lea said about this, you may see a variety of autoimmune and neurological illnesses that are occurring at what appear to be higher rates. So I have been in touch with three people who had shrinking of their cerebellum, for instance, part of the brain.

But we do not have good data to look at the rates, and be able to define what the rates are of these various individual conditions within the Gulf War population, or within military populations. And I think there are reasons for that, and that they are related to the overall obfuscation of Gulf War illness.

Congress directed the military to maintain databases of exposures, of troop movements, of illnesses and created a defense medical surveillance system back in the late 19nineties in which all the services' data would be linked.

However, at least three different people have looked at the accuracy of these records and found that the error rate varies from ten to thirty percent and sometimes is greater.

Mr. HARE. Doctor, I do not want to interrupt you, but could you tell me how do you treat——

Dr. NASS. Sure.

Mr. HARE [continuing]. A patient that is suffering from——

Dr. NASS. All I know how to do, and most other people who are doing this also, go symptom by symptom—so that if they have chemical exposures that they are sensitive to, you teach them about that condition and have them avoid the noxious exposures which can make them acutely worse for a period of time.

If they have diarrhea, there may be causes that are treatable. Some people have abnormal gut flora that you can treat with antibiotics or anti-yeast medications. There are other medicines that will frequently control the diarrhea. They all have sleep disorders. You find medication that helps them sleep.

And it is a combination of piecemeal interventions—trying to work on every one of these symptoms and trying to teach the patients how to choose a lifestyle that will allow them to live better, teaching their relatives about it, educating them that it is a real syndrome and people should not think they are crazy. And you can improve their function maybe 30 or 40 percent, but they certainly do not get cured.

Mr. HARE. Thank you, Doctor.

I want to thank the panel for taking the time to be with us this morning and I appreciate your testimony. Thank you very much.

Dr. NASS. Thank you.

Mr. HARE. We are going to bring up the third panel. While we do, I am going to recess the hearing for about 5 minutes and then I will be right back. Thank you.

[Recess.]

Mr. HARE. The Committee will now reconvene.

Our third panel is Dr. Lawrence Deyton, the Chief Public Health and Environmental Hazards Officer, Office of Public Health and Environmental Hazards, U.S. Department of Veterans Affairs.

He is accompanied by Dr. Mark Brown, who is the Director of Environmental Agents Service, Office of Public Health and Environmental Hazards, U.S. Department of Veterans Affairs.

And Dr. Timothy O'Leary, who is the Director of Biomedical Laboratory Research and Development Service and the Director, Clinical Science Research and Development, Office of Research and Development, U.S. Department of Veterans Affairs.

And Dr. Eugene Oddone?

Dr. ODDONE. Correct.

Mr. HARE. Dr. Eugene Oddone, who is the Director for the Center for Health Services Research in Primary Care. He is a Principal Investigator of the National Registry of Veterans with ALS, U.S. Department of Veterans Affairs.

Let me thank you all for coming this morning. I look forward to your testimony.

And, Dr. Deyton, we will start with you. Thank you.

STATEMENT OF LAWRENCE DEYTON, MSPH, M.D., CHIEF PUBLIC HEALTH AND ENVIRONMENTAL HAZARDS OFFICER, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS; ACCOMPANIED BY MARK A. BROWN, PH.D., DIRECTOR, ENVIRONMENTAL AGENTS SERVICE, OFFICE OF PUBLIC HEALTH AND ENVIRONMENTAL AGENTS SERVICE, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS; TIMOTHY O'LEARY, DIRECTOR, BIOMEDICAL LABORATORY RESEARCH AND DEVELOPMENT SERVICE, AND DIRECTOR, CLINICAL SCIENCE RESEARCH AND DEVELOPMENT, OFFICE OF RESEARCH AND DEVELOPMENT, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS; AND EUGENE ODDONE, M.D., MHSC, DIRECTOR, CENTER FOR HEALTH SERVICES RESEARCH IN PRIMARY CARE, PRINCIPAL INVESTIGATOR, NATIONAL REGISTRY OF VETERANS WITH ALS, VETERANS HEALTH ADMINISTRATION, U.S. DEPARTMENT OF VETERANS AFFAIRS

Dr. DEYTON. That is quite all right. Thank you very much, Congressman Hare, Congressman Brown. And I know Congressman Moran had to leave. Thank you for the opportunity to be here this morning to talk about these very important issues.

First, I think we all have to and want to express our honor and are moved by the experiences and examples of the veterans we heard from on our first panel this morning.

I must, and really want to, respond specifically to General Mikolajcik's moving testimony. I am an active clinician in the VA healthcare system. I help care for persons living with ALS and I have some appreciation of the struggle such a catastrophic condition brings to a person and to their family.

We all need to pay attention, very careful attention to the challenges the General has laid down before us today. That the General has so selflessly dedicated his energies to educating all of us about ALS inspires me and I know inspired Secretary Nicholson when they met recently.

General Mikolajcik's service makes me all the more proud to serve him and all of our veterans, and I thank you, General, for being here today.

My written testimony, Congressman, addresses three major topics. First is VA's efforts to improve clinical care and our understanding of the illnesses affecting veterans who served in the 1991 Gulf War.

Second, how these efforts have helped us respond to the healthcare needs of our troops fighting in this same region today.

And, third, VA's response to concerns about potential increased risk of ALS among military servicemembers.

As you are well aware, Mr. Chairman, every conflict in which our troops take part has the potential of both short-term and long-term health effects for those involved. The possible short-term health effects are the obvious risks of the battle.

The risk of longer term health effects are manifold and sometimes emerge years or even decades later. Those risks may be related to many factors including exposures to toxic substances, some

of which are known, others not, but may have their health effects emerge years or decades later.

VA has learned from past conflicts that the sooner we can collect health information on our troops and our veterans, the sooner we can initiate epidemiologic surveillance and well-designed studies on these populations of servicemembers to understand the longer term health effects of combat and establish a solid foundation of knowledge upon which we can build a coherent health program for our veterans.

I hasten to add the mission of combat is to accomplish the tasks assigned and protect our troops. Thus, the battlefield is a poor source of epidemiologic information. So we, the healthcare team caring for our veterans years later, are frequently left with less than perfect knowledge with which to understand those exposures to which these brave men and women have endured during their service.

That less than perfect knowledge may hinder our understanding of the cause of some of the health problems, but it does not keep us from providing world-class healthcare to our veterans then and now.

In order to better understand the health effects of the 1991 Gulf War, in 1992, VA established a Gulf War Veterans Health Examination Registry which offers comprehensive physical examinations and collects data from those veterans who participate.

As of June of this year, over 100,000 Gulf War veterans have enrolled in the Gulf War Registry and it continues to make new enrollments every day. In fact, over 7,000 veterans from the current conflict have enrolled.

Mr. Chairman, while registries help us reach out to the veterans and help us better characterize their health status, registries cannot replace well-conducted epidemiologic or biomedical studies of the health effects reported by those veterans. Thus, VA has initiated multiple epidemiologic and biomedical research studies to allow us to continue to provide knowledge on Gulf War related illnesses both to veterans and their families as well as to educate our clinicians.

Mr. Chairman, as the first Gulf War conflict ended, we all learned and worried about veterans returning from that theater with hard to diagnose, multi-system complaints. To better understand the causes and identify treatments, VA has funded the epidemiologic and biomedical research I just mentioned and also has established war-related illness and injury study centers to provide specialized healthcare for those veterans with difficult to diagnose or undiagnosed but disabling illnesses.

These centers have assisted many veterans and have contributed significantly to the medical literature on both the diagnosis and treatment of these real but vexing clinical situations.

One of the most important responsibilities we have in VA is to assure our veterans and their families are aware of the VA programs and information about how we can assist them with their healthcare needs. Thus, for our veterans who served in the first Gulf War, VA publishes and mails to over 400,000 veterans the Gulf War Review Newsletter and has also distributed over a million copies of a brochure summarizing VA benefits.

General Mikolajcik, with his moving testimony and his dedication to improve veterans' healthcare needs leads me to conclude my statement with some comments about VA's action in relation to ALS.

Mr. Chairman, VA became aware of reports of possible increased incidence of ALS among veterans in 2001. In that year, VA implemented a policy for referring Gulf War veterans' ALS disability claims to VA's central office for review and special consideration.

Since that time, VA's continued concern about possible increased incidence of ALS among veterans led us to create a VA ALS registry which has enrolled nearly 2,000 veterans.

In addition, VA has initiated multiple research projects to improve the diagnosis and treatment of ALS. And in 2005, VA asked the Institutes of Medicine to conduct an independent review of the scientific basis of all the relevant studies on ALS to help us determine the validity of the evidence connecting ALS and military service.

The results of that report concluded that although there are very few relevant studies which have been completed and there are significant limitations in the studies which have been conducted, the Institute of Medicine concluded there is limited and suggestive evidence of an association between military service and later development of ALS.

In response to that IOM report, Secretary Nicholson convened a task force to review the IOM's assessment. That task force has completed its review and Secretary Nicholson wants the Committee to know that all veterans who have or suspect they may have ALS, VA treats veterans with ALS. ALS is a catastrophic disease and veterans with significant impairment are eligible for priority category four which will assure they have access to VA healthcare.

It is the Secretary's view that the question of whether ALS should have presumptive service connection still requires more research. While preliminary studies as cited by the IOM show there may be some association, the research is not extensive enough to be conclusive.

The Secretary would like more research to see if a strong correlation exists and he has directed us today to help conduct that research.

Again, I want to thank you for calling this hearing. There are many topics that we have discussed today. And I want to particularly thank General Mik for his continued service to our Nation and to our veterans.

That ends my oral statement. I am happy to take any questions, sir. Thank you again very much.

[The prepared statement of Dr. Deyton appears on p. 61.]

Mr. HARE. Thank you, Dr. Deyton. Mr. O'Leary?

Mr. HARE. Just Dr. Deyton. I am sorry.

Mr. O'LEARY. I did not come with a prepared statement, sir.

Mr. HARE. Pardon me?

Mr. O'LEARY. I did not come with a prepared statement.

Mr. HARE. That is fine. This is my first hearing that I am chairing, so you will have to bear with me for my errors.

Okay. Thank you.

I just have a couple questions here. The Gulf War Newsletter which is a publication that the VA initiated to help veterans of the Gulf War and their families be more aware of VA healthcare and other benefits, it is reported that that newsletter has not been mailed out for over a year.

And I was wondering what have you done to ensure that the outreach to Gulf War veterans is being done on a regular basis, that that outreach is.

Dr. DEYTON. The Gulf War Registry is continuing. It is a very important publication for us and it is continuing to be released. Dr. Brown helps run that—he can provide a specific response.

Dr. BROWN. Yes. The last publication was July of 2006. We expect to come out with the next edition of that at the end of the summer. It is in preparation now.

Mr. HARE. Thank you.

Because they suffer from a multitude of illnesses, the treatment of Gulf War veterans is by most accounts pretty complex. I think we could all agree.

When you heard Anthony Hardie in his testimony today state that the VA's Office of Public Health and Environmental Hazards' Web site contains little information that might be of any use to Gulf War veterans and/or their health providers, could you tell the Committee what type of training or continuing medical education requirements are in place currently at the VA to ensure healthcare professionals have the most current and up-to-date information of the Gulf War illness?

Dr. DEYTON. Yes, sir. As I said, I am a practicing clinician in the VA system and I think the theme that we have heard from all the panelists today is that there is much more knowledge needed in all of these areas, more research needs to be done to better understand.

So as a practicing physician, I want to know everything I possibly can so I can treat my patient who comes into my clinic complaining of some of those multiple system complaints that Dr. Nass so specifically told us about on the last panel.

And so we have developed multiple education tools for VA clinicians, for veterans and their families as well, to help understand that long list of multi-system illnesses and diseases that could compromise a veteran's health.

There is a Veterans Health Initiative Program that our office runs that has consolidated what knowledge we know and are continually updating that knowledge as more research is revealed about both the symptoms, the diagnoses that might be applied to those symptoms, and the possible treatments for that long list of symptoms.

And I think Dr. Nass really hit the nail on the head. You really have to go through a very long list of clinical possibilities, take them one at a time, and examine each one fully and do the right diagnostics and try and treat them one at a time.

Mr. HARE. Let me ask again, Dr. Brown, are there other clinical education components that we provide to VA providers and the public?

Dr. BROWN. Yes. It is a good question. I think we see outreach to veterans and their families and we see education of our

healthcare providers as a top priority about veteran health issues in general and about issues surrounding Gulf War veterans, those who served in the 1991 Gulf War, and unexplained illness as a specific health issue.

And it is a long list. I would invite you to take a look at our Web site at www.va.gov/environagents and there is also a Web site specifically for Gulf War. And you can see some of these products.

We have, for example, this issue of unexplained pain and unexplained fatigue that you heard from some of the previous panels is a problem with veterans of the 1991 Gulf War. And so we pulled together what is called a clinical practice guideline which is essentially a tool kit for our healthcare providers to give them information about how to respond to these illnesses that we developed that is up on that Web site.

Another example you heard somebody mention earlier concerns brain cancer among some troops that were around where some chemical weapon munitions were blown up at the end of the war, when the 1991 cease fire was declared. There is some data now showing that some of those exposed may have greater risk for brain cancer. As Dr. Steele mentioned, it is a rare disease fortunately. But for those who it affects, it is obviously extremely serious.

We have information letters talking about the background and the medical issues surrounding that that a healthcare provider could read and that also a veteran and his or her family could also read.

I think if you look at our Web site, it may be that not everything is absolutely up to date as it possibly could be and that is something that we are continuing to work on, but I think we try to cover a wide range of health issues that are of interest to veterans and their families.

You received written testimony submitted for the record from Mr. Fahey, depleted uranium which is another concern of veterans and their families. We have background information on that. We also have information on vaccines and so forth.

I suppose the problem that we face is that there are so many risk factors that people have looked at that it is a challenge to keep up with it, but I think it has been helpful.

Mr. HARE. I know I am out of time, but just one question and then a comment.

Dr. Deyton, the General spoke this morning about an ALS task force. I think it is a wonderful idea and having the lead agency and, the other two items, the money and the other things that are necessary.

I wanted to know what your thoughts might be on that and do you believe that VA is taking—what direction you think the VA—if you think they are taking the right direction on ALS along the way.

Dr. DEYTON. I think General Mik's suggestion is very sound. And to have cross-agency, public and private communication and coordination to make sure all the bases are being covered and being done in a consolidated, organized way is brilliant.

And so both officially from a VA point of view, I cannot commit for the department, but I can tell you we would be at that table and wanting to be a major player in assisting with that task.

Mr. HARE. Thank you, Doctor. Mr. Brown?

Mr. BROWN OF SOUTH CAROLINA. Thank you very much and we certainly appreciate your testimony. And it has been a real interesting dialog as we had the three panels.

But my question would be that the Gulf War veterans are considered a disability if they contract ALS. Why would not all veterans be qualified with a disability compensation if they have ALS?

Dr. DEYTON. Certainly any veteran who has the diagnosis of ALS or other disabling condition like that can come to VA for healthcare. When I spoke with the Secretary's office this morning and my own feeling as a practicing clinician, we want to make sure those veterans know they can come and should be coming to VA for their care.

With the disabling conditions, they would likely be categorized in priority category four which is a higher priority so that they would be sure to get the medical care that they need.

The issue raised about all veterans and their increased risk of ALS is very complicated. I personally agree with the findings in the Institute of Medicine's report that there is an association that has been demonstrated by scientific research.

The Institute of Medicine also went on to say they could not attribute any known factor to that increased risk. And we heard on the first panel, particularly, several cogent arguments for what those factors might be.

General Mik's point is exactly right. We need the research to be done to help nail down what the etiology is and, very importantly, a parallel path development of effective treatments and effective diagnoses.

The whole point is to establish a diagnosis before there is serious irreparable damage to the nervous system. So how do we find men or women who might be developing this and intervene immediately to preserve their neurologic function before there is any major deficit?

I think the ALS registry that VA has started and Dr. Oddone has been running is a very important tool. The research that VA has been conducting in ALS both in diagnostics as well as in treatments for ALS and other like diseases is very important.

And, again, back to General Mik's point of view. Having a consolidated cross-government, public-private communication about these issues, I think, would be very important. And, again, VA would welcome the opportunity to participate in that.

Mr. BROWN OF SOUTH CAROLINA. You heard the testimony when General Mik said that it was 2 years before, I guess, before he was able to get some consideration after basically he was diagnosed.

The other members of the military that come down with ALS, how long before they are eligible to be treated as a class four, do you know?

Dr. DEYTON. That is a good question, sir. I think that that depends upon the diagnostics and the degree of impairment that that particular individual would have. So at the point of a diagnosis of

ALS, relatively significant impairment would likely have occurred and they would be eligible at that point based on that impairment.

Let me ask Dr. Oddone. Maybe you have some other factors or perspective on that.

Dr. ODDONE. Yeah. I think it is like General Mik said. One of the difficulties with ALS is that there is not a single diagnostic test that confirms the disease. And so it is time often a second opinion, the experience he had where he had a first physician that said this looks like it could be this, but I would like you to get a second opinion.

And so all of those sort of delay in time, unlike you would get with a heart attack or something like that where it is pretty clear. There is a marker in the blood that tells you what it is. There is an EKG that tells you what it is. It is not that clear always in ALS and so the process takes time.

I cannot answer how that might affect policy.

Mr. BROWN OF SOUTH CAROLINA. I am just concerned. I know that one of the things he also requested was some kind of a common data bank and that we do not have one available.

Dr. ODDONE. Sir, you know, I think one of the reasons that the VA funded the registry was to do that, was to try to collect as complete as possible a group of veterans who have developed the disease. That started in 2003, pretty soon on the tail of when we found out that there was an increased incidence of the disease in veterans who were deployed to Persian Gulf War.

And so one of the purposes of that was, A, to do several things. One, do more in-depth studies about cause and etiology of the disease and several of those are ongoing now.

Second was to provide a collection for those veterans so that when we would find out about treatments, that we would know how to let them know about those.

Mr. BROWN OF SOUTH CAROLINA. And I guess my question is, if we have got the data bank and we are actually using it, we ought to be able to have some method to be able to determine early detection. Even if you do not have a treatment, we ought to be able to at least not have to have someone wait for 2 years before we recognize, you know, in effect, he has been inflicted with that disease.

Mr. O'LEARY. If I may address that, sir. I think that VA research actually has a pretty coordinated and comprehensive approach to this problem of ALS, looking at causes, earlier diagnosis, methods to retard the progression of the disease, research on the use of adult stem cells to perhaps reverse some of the effects of the disease, and, then finally, for those people that are suffering very badly, to palliate the effects of the disease and help them to cope more effectively.

I think there is some very promising research that has been done on the development of early biomarkers which in combination may provide a clue that would allow us to reach a diagnosis much, much earlier in the disease.

Having said that, it is relatively early research. It needs some confirmation. It needs some time to prove that it is true because not every exciting research finding turns out to be confirmed in later studies.

But if this does prove to be true, it would be quite useful because that earlier diagnosis gives us the possibility then to intervene in the disease before so much destruction has occurred. And I think that is a really, really critical goal for us to achieve.

Mr. BROWN OF SOUTH CAROLINA. To the benefit side, what would it take to trigger allowing members of the Armed Services that contract ALS to become eligible for disability payments early on rather than wait until it is too late?

Dr. DEYTON. That is a complex question, sir. Let me try and I want to answer it in a couple different——

Mr. BROWN OF SOUTH CAROLINA. It is not a large number, right?

Dr. DEYTON. I am sorry.

Mr. BROWN OF SOUTH CAROLINA. It is not a large number, is it, outside of the Gulf War?

Dr. DEYTON. I do not know what the number would be. Dr. Oddone might——

Dr. ODDONE. I do not have a census. I know how many patients are in the registry. It is nearly 2,000 patients in the registry. At the beginning of the registry, we made some estimates about how many veterans we would have based on the total U.S. veteran population and we anticipated that it would be between 1,500 and 2,500 veterans at any given time.

Mr. BROWN OF SOUTH CAROLINA. So we are not talking about a tremendous amount of money, right?

Dr. DEYTON. I do not know how much money it would be, but it is really not the money. It is the right thing to do for the veteran.

Mr. BROWN OF SOUTH CAROLINA. That is my question and I am just trying to justify a good answer from you all.

Dr. DEYTON. I am sorry. Ask the question again.

Mr. BROWN OF SOUTH CAROLINA. Okay. My question is, what do we have to do to be able to qualify those veterans that are not involved with the Gulf War that come down with ALS? I mean, how can we qualify them for immediate benefits?

Dr. DEYTON. The Secretary has the authority to grant presumptive service connection to any category that he or she wants. Congress could also enact a requirement for us to do that.

Mr. BROWN OF SOUTH CAROLINA. Well, I do not know if we have got a bill that could track with that. Could you all persuade the Secretary maybe to do the right thing?

Dr. DEYTON. And the good news is that the Institute of Medicine report that we requested that they do to look at the evidence is in the Secretary's hands. He has read it and his statement today is very clear that he wants to invest in the research necessary to understand that connection better and better. And so we will be doing that.

Mr. BROWN OF SOUTH CAROLINA. And maybe he could do that as his parting action. That would be great.

Thank you all very much.

And I apologize, Mr. Chairman, for overextending my time, but this has absolutely been a great dialog.

And thank you all for participating.

Mr. HARE. Thank you, Mr. Brown.

Mr. Brown, I would not apologize at all. I think your questions were wonderful and thank you for hanging in with this rookie this morning.

Let me just close by thanking everybody that came this morning and into this afternoon.

I just want to say a couple things. If you would please convey to the Secretary the appreciation that I have in terms of the level four for ALS patients.

I have said on this Committee many times, and I know I am a freshman Member, but my opinion is I believe that we have a fundamental responsibility to do everything that we possibly could do for our veterans regardless of when they served, where they served, what branch they served in.

I cringe sometimes when I hear how are we going to afford it because to me, the question should be not how are we going to afford it. The statement ought to be we cannot afford to not do this.

I believe for people like General Mik and for other people and for the other witnesses that testified, the Gulf War vet that is still here with us, I think we have a moral obligation to do everything that we possibly can.

I hope that as we move down the road, and I talked to my friend here and colleague, Mr. Brown, about what we can do to try to help the General and other patients with ALS and coming up with the necessary funding. I always hope that we will err on the side of the veteran first and foremost and then worry about how we are going to figure it out on the other side because it is the right thing to do and, it sends an incredibly poor message, I think, if we make the veterans have to go through hoops that they simply cannot go through, cannot make it through, or we do not give them the information that they need to be able to get the kind of help that they are so desperately in need of.

So, you know, from this, I guess, very freshman Member of this Committee, I would hope that you would convey to the Secretary my sincere desire that—you know, I think Mr. Brown brings up a good point. Before he leaves, this would be a wonderful way, I think, of his leaving and to the new Secretary, whoever he or she may be, that we really lead by the presumption on our vets, that they are our best and our brightest and that we do have this moral obligation.

And, you know, we will figure out the money. I know we have PAYGO, but these are people who have given everything they have. And when you see somebody like General Mik—I am sorry.

Brigadier General MIKOLAJCIK. I wondered, Mr. Chairman, if I could I make another statement.

Mr. HARE. I was a Sergeant. You are the General, so go right ahead, sir.

Brigadier General MIKOLAJCIK. The VA talked about, we help all veterans that have ALS. Well, in my support group in Charleston, there is a veteran by the name of Tech Sergeant George Jarrell. He spent 24 years in the Air Force, served in Vietnam. He was on duty during the Gulf War, but not in the Gulf War. Because he is categorized as category eight, he did not even get as much help from the VA as the blocks on the table I had, nothing.

There is a huge difference between service-connected disability and just being a veteran. And we can continue to do more studies. This town is great for them. But it is time to make a decision. Secretary Principi had courage when he took the data that he had and moved forward and said we are going to grant service-connected disability. And I think as the Chairman has just said, we owe that to the rest of our veterans. Forget the studies. Make a decision and help them.

George has had to mortgage his house to put a ramp into it. Congressman Brown and his office had gone to the VA in Charleston to get him an appointment and he still does not have it.

I am sorry to be so emotional, but my emotion is honest. Thank you, sir.

Mr. HARE. Thank you, General. Again, thank you for being here and your courage is incredible and your voice in terms of standing up for veterans is wonderful. And this Nation owes you a tremendous debt of gratitude not just for the service that you had but for what you are doing now. And I want to thank you on behalf of the Committee and I appreciate your wife coming with you.

And, you know, I hope I have done a fairly decent job of chairing this meeting this morning. And when Congressman Michaud gets back, if you would tell him that I did not mess it up too bad, I would be honored.

But I thank you all very much for coming. And with that, the hearing is adjourned. Thank you very much.

[Whereupon, at 12:29 p.m., the Subcommittee was adjourned.]

APPENDIX

Prepared Statement of Hon. Phil Hare

The Subcommittee on Health will come to order. I would like to thank everyone for coming today.

Regrettably, Mr. Michaud, the Subcommittee Chairman had an emergency and is unable to be here today.

During this hearing today, the Subcommittee will examine Gulf War exposures of veterans, the incidence of ALS among Gulf War veterans and most importantly, where is the VA in conducting continuing research on Gulf War One exposures and what are they finding out about the current exposures in OEF/OIF veterans.

Many of the veterans who served in the Gulf War were exposed to a variety of potentially toxic substances during their deployments.

According the Research Advisory Committee on Gulf War Veterans' Illnesses more than 16 years after the end of Operation Desert Storm, a substantial proportion of veterans continue to experience chronic and often debilitating conditions characterized by persistent headaches, cognitive problems, somatic pain, fatigue, gastrointestinal difficulties, respiratory conditions, and skin abnormalities.

The Department of Defense and VA together have spent $260 million on Gulf War illness research. While there have been numerous studies and much research conducted on Gulf War Illness, there are still many unanswered questions.

Another aspect of Gulf War One service is ALS. ALS is a progressive and nearly always fatal disease that affects a person's nervous system. According to the Institute of Medicine's *Amyotrophic Lateral Sclerosis in Veterans, Review of the Scientific Literature,* there is limited and suggestive evidence of an association between military service and developing ALS.

Additionally, in a study sponsored by the Department of Veterans Affairs in 2003, researchers identified that the incidence of ALS in veterans deployed to the Gulf was twice as high as the incidence of the disease among those who did not go to the Gulf.

I look forward to hearing from our panelists on these very important issues.

Prepared Statement of Hon. Henry E. Brown, Jr.

Good morning. Chairman Michaud and Ranking Member Miller I want to thank you for holding this hearing to discuss important issues that have impacted many veterans, within my state of South Carolina and the Nation as a whole, who have served their country during the Gulf War. As a Member of this distinguished Subcommittee, it is my duty—it is our duty to provide our Nations veterans with access to the best heath care possible. It is our duty, perhaps even a moral responsibility for us here today, on this Committee to help those brave veterans who have helped defend our great Nation.

Today, I have the distinguished and dignified honor of introducing someone who answered the call of duty by helping his country when it needed him the most; and today he comes before us and asks for our help. His name is Brigadier General Thomas Mikolajcik. For many years, my personal friend and great American hero, Gen. Mikolajcik, or Gen. Mik as he is known by those closest to him, has been a leader in the Charleston community. First, as the commander of the C–17 wing based at the Charleston Air Force Base, and then as an active contributor to the Charleston Chamber of Commerce's military relations activities following his retirement in 1996.

While General Mik's dedication to the Charleston community would be noteworthy in any case, it is even more impressive when one realizes that his focus on the needs of his community come at a time when he is suffering from a debilitating

and deadly disease. In 2005, General Mik announced that he had been diagnosed with Amyotrophic Lateral Sclerosis (ALS). While many individuals would have immediately withdrawn under the pressure and impact of ALS, the General used it as an opportunity, and with much resolve and endurance doubled his efforts and dedication. In addition to continuing his commitment to the Charleston community, the General has devoted a great deal of attention to raising awareness within the community of ALS and improving the quality of life for ALS patients and their families. Thanks to his efforts, a new ALS Association chapter was formed in South Carolina, and the only ALS clinic in the state was founded at Charleston's Medical University of South Carolina. General Mik is truly an inspiration to many throughout the Charleston community, continually thinking of others despite the grave challenges he faces.

Numerous studies have shown that individuals who have served in the military have a high propensity toward being diagnosed with ALS. While the Department of Veterans Affairs has identified ALS as a Gulf War I-related disease, cases abound that show the spread of this disease among veterans is much broader. Indeed, a recent study showed that veterans of all conflicts have a 60 percent higher chance of being diagnosed with ALS than the general population. It has been nearly 70 years since Lou Gehrig made his famous speech and retired from baseball after contracting this horrific disease, and it has been nearly 17 years since the end of the first Gulf War; and yet little has been done about this disease and even less is known about its causes. The work of General Mik has also brought to my attention the growing number of veterans contracting ALS outside of service during Gulf War I. My office is aware of a number of cases in my district from veterans who have developed ALS where the VA has denied their claims because their service was not within the presumptive timeframe of August 2, 1990 through July 31, 1991. We don't have a good handle on how many non-Gulf War I veterans have contracted ALS, what military-related risk factors exist, or what we can do to decrease the chances of ALS among our veterans and military service men and women. This issue is of special concern as we continue to have troops deployed in OEF/OIF.

The story of General Mik serves as a testament to the need for leadership at the Federal level toward developing a comprehensive ALS research program and a clear VA/DoD policy ensuring that all veterans with service-connected-ALS receive the attention they deserve, regardless of whether or not they served during Gulf War I. We need an agency to step up to the plate and lead Federal research into the causes of ALS and how we can better improve its treatment. Most importantly, we need to begin these efforts **NOW**, before more veterans, including General Mik, succumb to ALS.

Prepared Statement of Brigadier General Thomas R. Mikolajcik, USAF (Ret.), Mt. Pleasant, SC

Chairman Michaud, Congressman Brown and Committee Members, thank you for this opportunity to testify.

My name is Tom Mikolajcik. I am neither an MD nor a PhD. I am a P–A–L–S. A patient with ALS.

I was diagnosed in October 2003. I was given a death sentence . . . and told to get a second opinion, while given a prescription for Rilutek which has limited value. Only by the Grace of God am I here to speak with you today. . . . And I have vowed to keep speaking until I no longer can.

Military veterans, like me, face a higher risk of this relentless killer. Fifty percent die in 1 to 3 years, another 20% die within 5 years and only 10% may live to 10 years. It was learned in 2001 that Gulf War veterans have two times the incident rate of the general population. We discovered in 2005 that all veterans dating back to World War II have 1.6 times the incident rate of the general population for developing ALS.

Four short years ago, the VA opened its voluntary ALS Registry. It registered 1,993 veterans suffering from ALS. I am sad to say, and it is unacceptable to me, that only 969 (less than 50%) are still alive today. And, ladies and gentlemen, that also means that somewhere between 1 out of 15 and 1 out of 30 ALS patients are military veterans. The government must step up to the plate on this issue!

We are currently exposing 100's of thousands more service members to the elevated risk of this disease. There will be young men, women, and families celebrating a return from Iraq and Afghanistan alive, who have no idea that they may soon be facing a certain death from ALS. We will have to answer those families when they

ask what the government has been doing to prepare for this onslaught. For this reason, the government is compelled to assume leadership of this issue.

If these soldiers were dying in the field . . . rather than quietly at home as a consequence of their service, we would leave no stone unturned. We would use the best existing resources and programs to make sure they had whatever they needed to survive . . . to ensure that no man or woman is left behind.

Some say that a lot of ALS research has taken place. My response echoes the famous words of President Lyndon Johnson: ***"Research is good, results are better!"*** It's been nearly 70 years since Lou Gehrig made ***his*** farewell speech—and we have basically nothing—one questionable drug in 70 years!? How many thousands of private farewell speeches must take place before we realize we're not doing everything we can? Will I have to give ***mine*** before an appropriate, large-scale, comprehensive plan to tackle ALS is carried out?

ALS is more complicated than a Rubik's cube which is many sided, with multiple connections and various colors—**like this one.** One must consider causes, therapies, biomarkers, genomics, existing drugs, patient needs, palliative care as well as all avenues of research. Who is in charge of ALS research today? I have found no one in charge! What is the strategy for solving this ALS Rubik's cube? I've found no strategic plan! Who oversees and is accountable for existing medical research activities for ALS? No one!

So, yes, there may be many ongoing efforts into ALS, but potential success is thwarted by little cooperation, coordination, and sharing of information. From my viewpoint and understanding, there is no one entity in charge or accountable.

These blocks or boxes represent ongoing ALS research. All are separate, none are connected and there is no communication among them. We have underfunded researchers across the country; each working in their own little "box". This approach has been unsuccessful thus far.

We need to open the doors of labs and encourage collaboration. There should be no more deaths due to protection of ALS related intellectual property or potential profit. . . . Some of us are in a hurry. Therefore, it is the government's absolute responsibility to direct research into a full understanding of ALS.

In other words, my hope would be that we just not think ***outside*** the box, but totally redraw it; enlarging it to fit the enormity of this horrific disease. Many people come to hearings with problems and needs. I come before you with a solution also. I fully understand bureaucracy's aversion to change particularly within an industry as large as medicine and with the number of government agencies already dabbling, **yes, dabbling,** in ALS research.

Let's look back to 1961, when our Nation made a commitment to put a man on the moon within the decade. One government agency was put in charge and it was supported by other agencies, as well as private industry and individuals. My proposal is very similar. It worked then, it should also work now.

THIS IS WHAT I PROPOSE:

Establish a Congressionally directed ALS Task Force with specific milestones and a time line. Within 30 days, establish an ALS Task Force made up of government agencies, ALS researchers, private ALS Institutes, patients and a facilitating team not related to ALS or the medical industry. Within 60 days, the Task Force should recommend which government agency will be in charge and the supporting roles of other agencies. Within 90 days, develop a strategic plan which outlines all avenues of research to be included. It must be comprehensive, forward looking and all inclusive. The strategic plan should also outline agency and researchers' accountability. An adequate and fair funding stream must accompany this strategic plan.

The decade of the nineties was the decade of the brain. However, we invested too little time and too few resources on research to understand diseases of the brain, especially such a devastating disease as ALS. Over 30 years ago our country launched a war on cancer. Because of that effort, we now have many treatments for this dreaded disease, even some cures. Isn't it time for us to launch a war on ALS and other neurodegenerative disease so that we can have effective treatments and even cures?

We designed and designated the Apollo Program to put a man on the moon. For ALS, we could call it The Hope Program—***H***elping ***O***ther ***P***eople ***E***ndure.

From this day forward, this new direction can be a model program that has one government agency, designated by Congress, which has control and oversight of a lofty objective—solving the ALS Rubik's cube. There are many private models of leadership to draw upon. Innovations have sprung up driven by those connected to the disease including several with which I am involved (ALS–Therapy Development Institute, ALSA, MDA and MUSC ALS Clinic). These efforts will succeed with public leadership that amplifies their private support into an integrated whole. In the

future, this model could be duplicated as a test bed for research on other diseases. Because of the similarities among neuro-degenerative and neuro-inflammatory diseases, advances in ALS research will likely be relevant to Parkinson's, Alzheimer's', Huntington's and others.

We must prepare to offer our soldiers, sailors, airmen and marines an opportunity to fight this disease. **We can not simply fight this battle defensively, hoping to limit exposure to environmental risk.** We must fight it offensively as well, with an appropriate medical arsenal. Let's do what it takes to finish this enemy off once and for all.

Congress can make the commitment, take the initiative, legislate a new way forward and hold agencies accountable. We have the intelligence, the resources, and the competencies. It's time to apply **leadership** to the ALS Rubik's cube to move this campaign in a new and uncharted direction!

Let's have the answer ready for our Veterans and the general population suffering from ALS. Let's show them they were worth a *real* investment and a *real* plan. Let us redraw and enlarge the "box" to allow for their futures.

Finally, and probably the easiest task, is to immediately establish and fund a national ALS Registry to ensure comprehensive patient information, tissue, genes, DNA, etc., are available for investigation. Such a registry will facilitate, even stimulate, additional research and research collaboration. This will provide ***"HOPE"*** for future treatment and increased understanding of this disease.

But what about veterans like me who may not benefit from these future discoveries and treatments? We owe our veterans treatment *now*, however limited.

Over 5 years ago, the Secretary for Veterans Affairs extended service connected benefits to Gulf War veterans like me based on the research study results. Since then new research has shown an increased incidence of ALS among all veterans. The Secretary for Veterans Affairs should act *now* with the same decisiveness and the same concern for veterans by extending veterans' benefits to *all veterans* suffering from this terrible disease.

I've attached a copy of a letter I gave to and discussed with Sec. Nicholson on March 23rd of this year.

Thank you for your attention and for giving me this opportunity to speak.

God Bless Our Veterans! And God Bless America!

***Included with my testimony is the letter which I presented and discussed with Secretary Nicholson on 23 March 2007.*

Mt. Pleasant, SC.
March 23, 2007

Secretary R. James Nicholson
Department of Veterans Affairs
Washington, DC

Dear Secretary Nicholson,

In 2001, the Veterans' Administration and Department of Defense rightly recognized the relationship between Gulf War service and Amyotrophic Lateral Sclerosis (ALS), commonly referred to as Lou Gerhig's Disease. At that time the VA duly decided that Gulf War veterans with ALS automatically received a service connected disability. It also expedited ALS cases because this relentless disease, which is a death sentence, progresses so rapidly. This decision was widely applauded because of the compassion it showed to those who have served our country so bravely.

Since that time, an important study conducted at The Harvard School of Public Health has concluded that not just Gulf veterans, but all veterans are a higher risk of developing ALS. The 2005 Weisskopf study found that veterans who have served at any time in the last century are at a 60% greater risk than the general population. In a recent review of all relevant scientific literature, the National Academies' Institute of Medicine concluded that "the implication is that military service in general-not confined to exposures specific to the Gulf War-is related to the development of ALS."

These findings would suggest that the VA is therefore only granting benefits to a specific portion of those exposed to whatever trigger is responsible for our veterans' increased risk. How can we differentiate between all veterans with a 1.6 higher incident rate and Gulf War veterans with a 2.0 higher incident rate than the general population?

Because of the appropriate precedent set in 2001 and the additional studies subsequent to that, the VA should now grant service connected disability to all veterans!

I would be more than happy to discuss this further with you or your staff. You may contact me at 843–971–5000.

Very respectfully,

Thomas R. Mikolajcik
Brig. Gen. USAF (Ret.)

Prepared Statement of Anthony Hardie, Legislative Chair and National Treasurer, Veterans of Modern Warfare

Mr. Chairman and Distinguished Members of the House Subcommittee on Health, thank you for holding today's hearing on Gulf War Exposures and highlighting the enduring national significance of these issues. It is truly an honor and a privilege to be here today, and I hope to help voice some of the concerns of the many who are not here to share in this privilege.

On January 17, 1991, much of America watched Operation Desert Storm unfold on their evening news, decisively ending the many long months of the massed troops' watchful waiting under Operation Desert Shield. Six weeks of aerial bombing—interspersed with cross-border incursions and the Battle of Khafji and followed by a 3-day ground war—and the Persian Gulf War 1991 was over.

But for many of the nearly 697,000 troops who served, our overarching Gulf War experience had only just begun.

For Members of the Committee who may not be familiar, Gulf War troops were exposed to a host of toxic exposures experienced, often in combination, including: multiple low-level exposures to chemical warfare agents, including from bombed munitions factories and detonated munitions bunkers; experimental drugs mandated without informed consent like Pyridostigmine Bromide (PB) pills intended to help survive nerve agent exposure; inhalation of the incredibly high levels of micro-fine particulate matter from the Kuwaiti oil well fire plumes; experimental vaccines like anthrax, botulinum, and others; inhaled and ingested depleted uranium (DU) particulate matter; smoke from the daily burning of trash and feces; multiple pesticides; and petroleum products and byproducts.

For some of us who developed lasting health effects from this veritable toxic soup of hazardous exposures, it came while still in the Gulf. For others, it did not come until sometime after returning home.

Hearing this list of exposures, most people would find it of no surprise that so many thousands of Gulf War veterans became ill, or that so many remain ill and injured today. And it should be no surprise that so many have developed diagnosable, serious conditions like ALS, MS, and others.

What is stunning is that 16 years later, there are still few tangible results that might improve the health of those who became ill and remain ill. And we still have little information of any value to provide to Gulf War veterans or their health care providers that might help to improve Gulf War veterans' health.

Years were squandered disputing whether Gulf War veterans were really ill, studying stress, reporting that what was wrong with Gulf War veterans was the same as after every war. An incredible amount of effort was put into disproving the claims of countless veterans testifying before Congress about chemical and other exposures. Some of that negative effort appears to continue even today.

It is stunning that after nearly two decades, we still have little information to provide to Gulf War veterans who remain ill from their service.

It is true that VA does still have an open door for Gulf War veterans to be seen at VA medical facilities.

However, being seen is not the same thing as being treated.

The VA's Office of Public Health and Environmental Hazards website contains little information that might be of any use to ill Gulf War veterans or their health providers. Much of the information provided is dated between 1996 and 2001, years before the more recent research discoveries related to ill Gulf War veterans that affirm what Gulf War veterans have been saying all along—that their Gulf War exposures are what made them ill.

In July 2006, the VA's "Gulf War Review" included an article entitled, "Straight from the Source: VA's Environmental Agents Service is Serious About Communicating With Veterans." That issue, a year ago, was the last issue published.

For Gulf War veterans like me whose "Kuwaiti Cough" has never left after having coughed up thick black sputum while still in the Gulf and for several weeks after returning home, the report related to oil fire smoke and petroleum notes on the Office of Public Health and Environmental Hazards website would seem to be of par-

ticular interest. Perhaps its lack of usable content, indicative of the lack of attention being paid to these issues, is at least in part related to the fact that its stated principal author was not a leading scientist, but instead a community college communications/journalism student Summer Intern.

I have heard from countless other Gulf War veterans that they, like manyVietnam veterans before them, have stopped going to the VA, or have simply given up, and have done their best to adapt to the substantial lifestyle changes required by their disabilities, which may or may not be compensated for these disabling conditions incurred in service.

In addition to the commonly recognized long wait times and difficulties in the claims process, Gulf War veterans have had unique and special challenges due to the currently medically undiagnosable nature of many of their health conditions. In May, a VA report showed that only one in four undiagnosed illness claims for Gulf War veterans has been approved. And, at a Wisconsin Department of Veterans Affairs conference in January on Gulf War veterans' illnesses, we heard service officers telling their success stories of alternative methods in achieving service-connection for ill Gulf War veterans that bypassed the near impossibilities of undiagnosed illness claims. Clearly there remains much to be done to improve the disability claims process for ill Gulf War veterans.

On a more positive note, I was encouraged during last week's meeting of the Research Advisory Committee on Gulf War Veterans' Illnesses on which I serve to hear Dr. Robert Haley and his team describe their research goals of identifying diagnostic criteria for ill Gulf War veterans. Success in achieving these goals should finally help to pave the way for effective treatments.

And I remain encouraged by current efforts in the U.S. Senate to provide funding for Gulf War health research within the Department of Defense Congressionally Directed Medical Research Program budget focused on treatments that may aid ill Gulf War veterans.

The five-point statement of goals that came from Gulf War veterans more than a decade ago still holds true today: Gulf War veterans deserved then and deserve now an assurance that an exhaustive investigation has been fulfilled to identify all possible Gulf War exposures; that appropriate scientific research is promptly completed to connect known or potential Gulf War exposures with health outcomes; that medical treatment is based on that scientific research; that compensation is provided to those veterans left disabled by their military service if the health conditions cannot be reversed; and that every effort is made to ensure that never again can what happened to Gulf War veterans be allowed to happen.

For the thousands of living, ill Gulf War veterans, it is time to make good on our Nation's enduring promise of caring for those who have borne the battle, and their widows, and their orphans.

Prepared Statement of Denise Nichols, MSN, Vice Chairman, National Vietnam and Gulf War Veterans Coalition

Good morning Congressman Michaud and Representatives of the VA House Health Subcommittee and the audience in attendance this morning. I am honored to be here today representing the National Vietnam and Gulf War Veterans Coalition other Gulf War Veteran's groups that came forward to our elected representative since shortly after we returned from Operation Desert Storm in 1991.

I am Denise Nichols a Gulf War veteran and retired registered nurse with an MSN who served along the border of Saudi Arabia and Iraq in 1990–91 with the USAFR out of the 32nd Aeromedical Evacuation Group, Kelly Air Force Base, TX. When deployed all the Air Force Aeromedical Evacuation resources came under the 1611 AES(P). Our facilities were deployed throughout the theater with units at KKMC, KFMC, and all along the border of Saudi Arabia, Kuwait, and Iraq.

My particular Mobile Aeromedical Staging Facility (less than 50 people) was located at Log Base Charlie between Rafha and Hafa Al Batin. Our unit was theoretical in the exposure zone from Khamisiyah bunker complex demolition since we were assigned to the 44th Medical Group with the Army 7th Corp. Although it appears that the Air Force units were never included in lists provided by the DoD despite all my efforts with DoD during the time of the Office of Special Investigation of Gulf War illness and all the other committees and boards during the 1990's. The Army COSCOM unit was down the tapeline Road toward Hafa al Batin and a bit further was the Army Engineer Brigade site that was over the 37th Engineers that actual did the demolition. In the direction toward Rafha were the Army Hospitals

(3) we received patient flow from the closest one being an Alabama Army Guard Medical Hospital I believe it was the 115th or the 110th.

I can tell you now that the symptoms of Gulf War illness began to appear when we hit Riyadh and then as we moved forward thru KKMC to our forward location. We just were not fully aware of what the symptoms were representing at the time. We had rashes, visual sensitive to light, joint aches, urinary urgency, and diarrhea occurring. When you are in a desert environment and you are at war your job and duty comes first. We also had weird accidents I called them the clumsy/stupidity type accidents—falling from stairs of buses is but one example and then the weird ones of troops breaking training and handling explosive ordnance they found. We also had respiratory problems surfacing but again a lot of these symptoms were downplayed. And of course all the tens of thousands of alarms which were going off and we were being told that they were false. We had had our first round of anthrax shots in Riyadh and being a nurse I insisted that it be documented on my international immunization record (Type A vaccine but no lot number recorded and date). Probably not too many got documented because they had us signing a roster, which I have been told was lost in transit. We also were order to take the PB tablets. We also had to deal with the sand flies—leichmanasis. We also had pesticide spraying occurring at all the locations of troop deployment within Saudi. We also had shots on mobilization. Despite having been in charge of our mobilization shot scheduling for our whole 32nd Aeromedical Evacuation Group and I believe that our unit personnel were at the highest level for compliance for required world wide duty we still had additional shots thrown at us in the deployment line to include IGG, polio vaccine, and hepatitis and others. I had attempted personally to assure that my shot record was current so I was surprised when more shots were thrown at us. I had already as a medical person gone to Lowry AFB in Denver to get my hepatitis shots that I knew would be required for medical personnel and that is based on building up immunity levels. I had also pushed to have pre-deployment dental review done in Denver. I was in Deployable Ready status and didn't want anything to slow us down when we were called to report because we would be busy as officers being sure that all our unit personnel and equipment was ready to go.

The symptom that I believe we all missed was the mental irritability/mental cognitive/neurological functioning changes that began to surface when we hit Riyadh. This showed up in weird behavior that I now can attribute to behavior much like Brain Concussion cases where you have a change in mental cognitive and behavior functioning. This was not PTSD!

Since our return from the Gulf War in 1991, the Gulf War veterans were directed to the DoD/VA Clinical Evaluation Program, these programs have all but died because of VA neglected. Testing that was done in these programs to include EEG's, EMG's, and neurocognitive functions and many other tests were never compiled and released to the veterans or to the researchers that would follow. Many research studies listed in the Presidential Advisory Report have never been published.

In the majority of the VA Hospitals there is no information posted directing the Veterans of Operation Desert Storm Veteran Gulf War 90–91 how to access this program i.e. the Registries and what list of tests to anticipate. The Environmental Agents names and locations within each VA are not posted and therefore veterans seeking help have no information. The Gulf War veteran support groups at the VA hospitals were quickly dismantled. Some of our veteran advocates have asked individual VA's to place posters and information and provide the information desk with information that occurs immediately after we bring it to their attention but slowly every time the information vanishes.

The registry was suppose to be an ongoing program and updated but that has not occurred. Physicians and health care providers at the VA have not kept up on the advancements made and are not well informed. So a sick Gulf War veteran appears at their doorstep there is no information and the physicians and staff don't even have knowledge of the latest research findings. The Veterans themselves like Anthony Hardy, myself and many others of us try to bring materials to them and update them. Thank goodness I did this with a VA Emergency room doctor because it was shortly thereafter one of our young female veterans presented to that ER after being told by staff she called by phone she was just having indigestion. Well she was having an MI (myocardial infarction/heart attack). He took her seriously and did an EKG and she remembers him being astonished. She was quickly given a coronary catherization and taken to surgery. She lived others I know that went for help died because of lack of examining our Gulf War veterans. The data on heart conditions has not been shared. The data gained from autopsies and cause of death is not shared. This is simply not acceptable to have clinical staff that are not knowledgeable and to have valuable data and statistics not available.

The expertise on treating a multitude of toxic exposures is not within the VA. Very few Gulf War veterans that came to the VA even got a true physical neurological assessment the kind you do at the bedside not with all the brain scans etc. Therefore they were never truly assessed, then ordered follow up neurological testing. As a nurse with a master's degree I was taught the basic physical assessment that medical students are taught and I was astounded at the lack of physical neurological assessment. I was also astonished to have Drs like Victor Gordon that had done SPEC SCANS on many Gulf War veterans that showed abnormalities to be discounted. I had many words over the years with people like Dr Fran Murray that were denying the findings by SPEC and PET Scans and saying they were not valid. I was also upset that basic blood work to examine our hormones, adrenal, thyroid and pituitary functioning were not tested. I was upset when I asked early on for heavy metal testing and it was denied. I wondered if they were really wanting to find answers and give us competent care and diagnosis.

They do not even ask physicians in the civilian world involved in environmental health or anti aging which is a board certified field to be involved in training their physicians. In fact it has been documented that these doctors have approached the VA headquarters and different VA's to offer their expertise and to help train the physicians that are seeing Gulf War veterans and they were turned down! There are advances in the treatment of these conditions and also in the area of Chronic fatigue and Oxidative Stress that could immediately benefit Gulf War veterans who are suffering from ill defined or undiagnosed illnesses. We have had many veterans go to civilian doctors for help and this is unacceptable when they fought the war they were told to fight and have to find money to go to civilian doctors. It is also unacceptable for ill patients who look to doctors for relief to have to be bring in stacks of research that shows the direction the physicians should be examining and then to be ignored. It is unbelievable that patients, our fellow veterans—this country's veterans—who are ill suffering with neurological cognitive damage and other bodily system damage are having to share the expertise and teach doctors what they should know and practice and how they should be looking, examining, and testing the veterans.

The VA Newsletters to veterans has not been distributed for years. The VA central office has not responded to our request to update manuals, keep the newsletters up, or develop a means of keeping their staff informed of research findings throughout the years since 1990–91. The VA is also dismantling the Environmental Agents at each VA hospital or are not replacing them as they leave.

When veterans bring them research findings that could help the veterans even providing reprints and Drs and researchers names and phone numbers I doubt they even read the material much less try to make improvements in clinical care of the Gulf War veterans at their facilities.

A case in point at a brainstorming session at the CDC conference in 1999–2000 with a physician, I pushed the idea of checking the veterans for hypercoagulation (meaning thick blood that decreases the ability for the blood to flow to all major organs). This condition is similar to what I saw as a critical care nurse in at Wilford Hall USAF Hospital that resulted in Disseminated Intravascular Coagulation. The symptoms that we were experiencing that led me to this idea was the bleeding gums, the nose bleeds, the uncontrollable menstrual cycles, and the bleeding in stools. Sadly our females were not worked up but given hysterectomies early in life as a result. This is also a condition that had previously been studied in Chronic Fatigue patients and can be treated. An independent study was done and all Gulf War veterans in the study were tested by HEMEX Labs in Phoenix, AZ and all were found to be abnormal. The exploratory study and results were published in November 2000 in the Journal of Coagulation and Fibrinolysis, a peer reviewed journal. I had my own blood in that sample and the veterans that I contacted throughout the country to send in samples had theirs. This was a small sample study but represented a cross section of branches of services, location in theater, duty titles, etc. I took the published study in and briefed my primary physician, a hematology specialist, and gave her all the authors names and contact information. I asked her treat me for the condition she refused having previously told me her hands were tied in regards to Gulf War veterans with Gulf War illness. I asked her to start testing the other veterans of the Gulf War at the VA Denver Hospital. Not getting anywhere I was rightfully upset and at that time she offered me a consult to psychiatry. Here we had found a clue to help in our treatment, an independent civilian lab had gone in debt testing our blood and yet the VA was going to ignore the clues. I really was upset a week later when I found out the Director of the Lab at the VA hospital Denver was the EDITOR for the journal that published the study. That was in 2000 now in 2006 the VA funds a study into hypercoagulation. Now I ask you why not just start testing in the clinical area and treat! Why not read the current work on

Chronic fatigue that is looking at HPA axis abnormalities and start testing every Gulf War veteran at that facility re blood work on adrenal, pituitary, thyroid, and hormones. Test and treat! The values on abnormal lab work that would be found in Gulf War veterans could then be shared with the researchers. Why is research being treated separate and distinct from clinical testing and care? These two areas should be interlinked so clinicians feed in the data that researchers need and researchers when they find a treatment by small clinical trials can readily and quickly share their findings with clinicians and large scale treatment trials would be integrated more quickly in the clinical area. I offer my observations that this would be cheaper and more effective to enhancing the clinical diagnosis and care of Gulf War veterans. Much of the research could be done at a savings by integrating the sampling and testing by using clinical abilities and facilities (and cost) that are present and available at VA hospitals. We would get answers much more rapidly. This is but one example of our continuous saga of Gulf War veterans illness being ignored, mishandled, and not addressed in an effective manner!

The veterans that have developed symptoms of ALS or MS often have to be told to go outside the VA to get tested to find out if they have that diagnosis. The first veteran I knew with Gulf War illness that developed into ALS was Colonel Don Kline a wing commander of the Air Force who served in the Gulf. I met him in 95 while organizing the Unity Conference for Gulf War Veterans in Dallas, I convinced he and his wife to attend the meeting. He was already in a wheelchair with respiratory assistance. He died shortly after that. He had prior to developing the symptoms, luckily had left the military and was hired by Delta and Delta took care of his medical needs. The next one I met was Major Mike Donnelly AF F16 pilot—Top Gun Bred! . . . and soon after I met Captain Randy Hebert USMC(who had gone through the breech into Iraq), I took each of them to Representative Shays government Reform Committee to testify. Mike Donnelly's family took on the cause and advocated for answers for the Gulf War veterans with ALS, they sent their son all over the world for medical consults and in there pursuits I believe the number of Gulf War veterans we found with ALS was 60 and that is when the VA started quietly caring for that group but without a law to cover them as being presumptions or service connected. I have found in my travels and in my communications with veterans in person, over the phone and Internet others who had suffered and died without proper assistance from the VA. Major Mike Donnelly died 2 years ago and I am not sure of Major Hebert's status. This same situation is repeating itself with Gulf War veterans with MS. I believe we now have an estimated 500 cases of Gulf War veterans with MS.

We have asked repeatedly that the VA provide data on all known diagnosed illnesses that are being experienced by Gulf War veterans to include all diagnoses including on the top of the list all neurological autoimmune type diagnoses, cancers of all types, kidney diseases, thyroid diseases, liver diseases, respiratory diseases, the whole picture of all organ diseases. We need a semiannual account of the numbers that are showing up in the diagnosed illness category. This is possible through each VA hospital and thru central VA Health Affairs. We are asking that this data be mandated to be collected and updated at least semiannually and available for all on the VA website. Only in this way can practitioners, patients and researchers be aware of the health problems that are developing and then act proactively to screen other Gulf War veterans that they see. In this way the Gulf War veterans have a chance at early diagnosis and life saving care and treatment. Again we have gotten no ACTION on this item. Independently I was given data on the cancers that had been diagnosed in Gulf War Veterans from 1991–1995, that was data directly from within the VA system. I have copies of the actual data collection sheets. I have presented this data to the VA RAC GWI and to many members of the House and Senate. We also have an earlier listing that was obtained by Congressman Upton. As a nurse I was astonished at the numbers and types of cancers. I even consulted by phone to an Oncologist specialist in Texas that consults with the military hospitals and shared the data with him and he was also very concerned and frankly astonished. Early on I had reports of veterans with multiple cancers in single individuals having been diagnosed and one of these individuals even went to the Mt Sinai Hospital in New York for treatment on her own, sadly I feel she has died without any help from the VA because contact after she went for help ended. These are just a few of the snapshot pictures of the situation that still persists in the VA as far as clinical diagnosis, care, and treatment.

We need to have a law that offers the Service Connection to ALS, MS, Brain Cancer, and any other disease that is found to be above the expect rate of occurrence in the general population. These need to be added to our presumptive list by law not by arbitrary action of the VA that can change and does not get publicly covered. Consideration must be given to giving the veteran the true benefit of the doubt

when you are exposed to radiation, chemicals (pesticides and nerve agents, jet fuel and other service related exposures), biologicals (including vaccines), endemic diseases in the area of operations. By having the data base public to all we do the right thing by shining truth on the subject. WE served our country proudly and the debates must end. This country dishonors its servicemen and women to do no less and it sure doesn't show "Support the troops" to speak the words and not carry through in a timely manner. And doing battle with the VA which writes the contracts to IOM that is truly not independent is a deception to the troops, the families, and to this country's sworn duty to care for its troops and veterans. The rat's maze of circles of different government entities of denial must be stopped and the broken system put aside!

The Gulf War veterans are also reporting problems with vision and dental problems but unless they are 100% they are not seen and assessment and data on that part of the picture is ignored. They are left to fend on their own and the total picture of our rapidly declining multi system failure is not seen. Too many young Gulf War veterans have ended up with full dental extractions and dentures with no exploring for the cause or connecting problems. This ties in with oxidative stress theory.

Jim Binns and the VA RAC GWI have written a letter months ago to the Secretary of the VA recommending other advisory Committees in the area of clinical care and benefits to be formed for Gulf War Veterans from Operation Desert Storm . . . NO ACTION still after 16 years. Will you consider making that into a law as our RAC GWI was brought about.

In regards to Research we need answers—diagnostic biomarkers and treatments now! But do not research us into the GRAVE. Integrate the Research and the clinical testing now so that more veterans can get answers and possibly some treatment to help them stop the health decline. WE have all advocated for a targeted response in research to Diagnostics, biomarkers, and treatment. WE have asked for defense appropriations and defense authorization to be at the level it was prior to 911 for the Operation Gulf War Veterans from 1990–91 and it is like we are now the forgotten ones. The MS society has asked for 15 million. The Gulf War illness Advocates have asked for 30 million this money will finally be directed and focused in the Right direction thanks to the VA RAC GWI. Our money from 1991–2006 was misspent on stress/PTSD/ psychologist coordinated research. That time has passed. WE got 5 million for Fy06 funding and those reviews were just completed by the CDMRP Committees of which I was proud to serve as a Scientific merit reviewer. In FY07 we got 0 dollars. It was past due to involve the suffering veterans into the review process as oversight directly so we support the CDMRP program.

So much to inform you of in a short time and I have only hit the highlights and a few examples. I thank the Committee for having this hearing it is long overdue and we hope that it stimulates not only more hearings and a response to our funding needs but also to real action that fixes the broken system we enter in 1990–91.

Thank you and I would be overjoyed to address any questions you may have.

Prepared Statement of Meryl Nass, M.D., Internist and Hospitalist, Mount Desert Island Hospital, Bar Harbor, ME

Thank you for inviting me to testify before this Health Subcommittee. My name is Meryl Nass, and I practice internal medicine in Bar Harbor, Maine. I have conducted a specialty clinic to treat patients with fibromyalgia, chronic fatigue syndrome and Gulf War illnesses for 8 years. I also have a longstanding interest in the scientific evaluation and prevention of bioterrorism, particularly anthrax. Since 1998, I have spoken and written about the many soldiers and veterans who became ill after receiving anthrax vaccinations, usually with illnesses indistinguishable from Gulf War Syndrome. I hope to clarify outstanding questions about the vaccine in this talk.

Is There a Gulf War Syndrome?

How can I possibly ask that question, 16 years after the Gulf War ended? I brought it up because many people still deny the reality of this frequently serious illness. Last week, a new patient of mine, who presented with a severe, classic case

of Gulf War Syndrome (per the CDC's case definition,[1]) and was unable to work, informed me that his VA doctor did not believe in Gulf War Syndrome. He had never been given a diagnosis, and both he and his wife wondered if his problems were 'all in his head.'

Six months ago, the Washington Post ran a front page article on Gulf War Syndrome titled, "Funding Continues for Illness Scientists Dismiss" written by David Brown, a physician journalist. Brown misrepresented the findings of the Institute of Medicine, claiming it "reached the same conclusion that half a dozen other expert groups had: Gulf War syndrome does not exist."[2] Brown set up a straw man he then knocked down: that there is no cluster of symptoms *unique* to Gulf War veterans. He is correct: the symptoms of Gulf War Syndrome are not unique. Instead, they overlap closely with those of chronic fatigue syndrome, fibromyalgia, multiple chemical sensitivity, and irritable bowel syndrome.

But why should anyone expect Gulf War Syndrome to be a novel illness? The body has only limited ways of responding to environmental insults. Different noxious exposures can cause identical lung or kidney diseases, or cancers. Although Gulf War Syndrome may not be absolutely unique in its clinical features, the development of this syndrome in 25% of U.S. veterans of one war is unprecedented.

According to the 2004 Report of the DVA's Research Advisory Committee on Gulf War Veterans' Illnesses, there are an estimated 200,000 Gulf War 1 veterans with chronic, 'Gulf War' illnesses related to their deployment.[3] According to the Washington Post's David Brown, 199,000 Gulf War veterans receive compensation for such illnesses.

Why Is This Illness so Often Dismissed?

DoD and DVA together have spent $260 million on Gulf War illness research.[4] But the research findings are often contradictory; a large number of studies focused on psychological factors instead of physical illness; and there have been very few breakthroughs. According to John Feussner, M.D. (in the aforementioned Washington Post article) who was DVA's chief research officer from 1996 to 2002, "After hundreds of millions of dollars and a decade or better of research, we really haven't made any significant findings."

However, the research methods used in these studies have been repeatedly criticized by GAO. For example, models investigating sarin exposure and subsequent illness were inadequate to identify areas of sarin exposure.[5] Insufficient coordination and analysis of the huge Gulf War research portfolio has persisted.[6] Media reports have focused more on the lack of a unique syndrome and the negative studies than on the clinically relevant, validated research results.

Gulf War Syndrome does not have an ICD–10 code. It is not described in medical textbooks yet, and it is not taught in medical schools. The massive, confusing body of published research is extremely difficult for the non-specialist, let alone a journalist, to understand. Veterans have so many symptoms they often appear to have psychiatric, rather than physical, illness to uninformed medical practitioners. Therapies recommended by the DVA emphasize the use of psychiatric medications as pri-

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[1] Fukuda K et al. created the first definition of Gulf War Syndrome in this paper: Chronic Multisymptom Illness Affecting Air Force Veterans of the Gulf War. JAMA 1998; 280: 981–988.

[2] Brown D. Funding Continues for Illness Scientists Dismiss. Washington Post. December 3, 2006. A1.http://www.washingtonpost.com/wp-dyn/content/article/2006/12/02/AR2006120201291_pf.html

[3] VA RAC 2004 Report: www1.va.gov/rac-gwvi/docs/ReportandRecommendations_2004.pdf "A substantial proportion of veterans of the 1990–1991 Gulf War continue to experience chronic and often debilitating conditions characterized by persistent headaches, cognitive problems, somatic pain, fatigue, gastrointestinal difficulties, respiratory conditions and skin abnormalities . . . Research studies conducted since the war have consistently indicated that psychiatric illness, combat experience, or other deployment-related stressors do not explain Gulf War veterans' illnesses in the large majority of ill veterans. . . ." Progress in understanding Gulf War veterans' illnesses has been hindered by lack of coordination and availability of data maintained by DoD and the Department of Veterans' Affairs."

[4] 2005 Annual Report to Congress on Gulf War Veterans' Illnesses. Page 39 http://www.research.va.gov/resources/pubs/GulfWarRpt05.cfm

[5] GAO–04–821T. June 1, 2004: "The modeling assumptions . . . were inaccurate because they were uncertain, incomplete and nonvalidated." "DoD and VA's conclusions about no association between exposure to CW agents and rates of hospitalization and mortality . . . cannot be adequately supported because of study weaknesses."

[6] GAO–04–767. June 1, 2004: "Interagency coordination of Gulf War illnesses research has waned. In addition, VA has not reassessed the extent to which the collective findings of completed Gulf War illnesses research projects have addressed key research questions. . . . This lack of comprehensive analysis leaves VA at greater risk of failing to answer unresolved questions about causes, course of development, and treatments for Gulf War illnesses."

mary treatment modalities.[7] *All these factors have conspired to create a smoke screen that both the ill veteran, the competent medical practitioner and policymakers have trouble penetrating.*

A closely related smokescreen has been created around the safety of anthrax vaccine and its role in Gulf War illnesses.

Despite the finding by a Senate Committee in 1994 that anthrax vaccine was being considered as a possible cause of Gulf War illnesses,[8] and the statement by the Persian Gulf Veterans Coordinating Board that "all potential causes [of Gulf War illnesses] that have been identified are being investigated,"[9] when I first reviewed the portfolio of Federal research on GWS in 1999, I was surprised to find that of 166 studies listed, none looked specifically at anthrax vaccine.[10] Since 1999, a dozen Congressional hearings and seven expert Committees have investigated anthrax vaccine safety and made research recommendations. Yet, since then the DVA and DoD have failed to correct the omission of anthrax vaccine-specific Gulf War illness research.

I reviewed the (latest available) 2005 Annual Report to Congress on Gulf War Veterans' Illnesses, which lists a total of 300 separate studies at a cost of $260.6 million dollars.[11]

Contrary to the DVA and DoD research funding priorities, anthrax vaccine has not been dismissed as a possible cause of Gulf War illnesses by the experts. Since 2000, three expert panels have reviewed Gulf War illnesses and commented on the possible role of anthrax vaccine. Here are some of their findings and recommendations:

1. Institute of Medicine Committee on Health Effects Associated with Exposures During the Gulf War:[12]

- Studies of the anthrax vaccine have not used active surveillance to systematically evaluate long-term health outcomes.
- The committee recommends a long-term, longitudinal study of participants in the Anthrax Vaccine Immunization Program.
- The committee recommends a careful study of current symptoms, functional status, and disease status in cohorts of Gulf War veterans and Gulf War era veterans for whom vaccination records exist. These cohorts should include nonimmunized, deployed and nondeployed Gulf War veterans; and immunized, deployed and nondeployed Gulf War veterans.
- Future research should consider issues related to potential long-term adverse effects of the combinations of these and other vaccines routinely given to armed forces personnel.

2. 2004 Independent Public Inquiry on Gulf War Veterans' Illnesses (UK) report:[13]

- It is of the highest importance to discover the cause or causes of the illnesses from which the veterans are suffering, because only if the causes can be discovered is there any prospect of finding effective treatment.
- A third strong candidate must be the multiple vaccinations, especially the combination of anthrax and pertussis. This would be the best explanation for those few [ill veterans] who received the vaccines but were never deployed to the Gulf.
- On balance, the inquiry concluded that the immunological impact of the multiple vaccinations administered was unusual, possibly unprecedented. The consequences for health of this vaccination programme remain uncertain.

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[7] http://www.oqp.med.va.gov/cpg/cpgn/mus/mus_cpg/frameset.htm

[8] Senate Committee on Veterans' Affairs. Is military research hazardous to veterans' health? Lessons spanning half a century. December 8, 1994. S. Prt. 103–97. http://www.gulfweb.org/bigdoc/rockrep.cfm

[9] Persian Gulf Veterans Coordinating Board. Unexplained illnesses among Desert Storm veterans. A search for causes, treatment, cooperation. Arch Intern Med Feb 13, 1995; 155:262–8.

[10] Research Working Group of the Persian Gulf Veterans Coordinating Board. The Annual Report to Congress: federally Sponsored Research on Gulf War Veterans' Illnesses for 1998, Appendices. Department of Veterans Affairs. June 1999. pp 7–13.

[11] http://www.research.va.gov/resources/pubs/GulfWarRpt05.cfm. Not one title mentions anthrax vaccine.

[12] Institute of Medicine Committee on Health Effects Associated with Exposures During the Gulf War. Gulf War and Health. Volume 1: Depleted Uranium, Pyridostigmine Bromide, Sarin, Vaccines. National Academy Press, Washington, DC. 2000.

[13] http://www.lloyd-gwii.com/report.asp

3. VA Research Advisory Commmittee on Gulf War Veterans' Illnesses: [14]

- That VA work with Federal agencies (CDC, NIH, DoD) involved in conducting vaccine trials that include administration of AVA [anthrax vaccine adsorbed] to ensure that these trials include follow-up assessments of study subjects a minimum of 5 years after inoculation. Such studies should utilize methods and instruments capable of capturing chronic symptoms and cognitive difficulties similar to those experienced by Gulf War veterans.
- That VA conduct a retrospective cohort study that compares chronic symptoms and diagnosed conditions experienced by veterans who received AVA as part of the military's mandatory anthrax vaccination program to those of a comparable group of veterans who did not receive this vaccine.

The research to determine the extent of anthrax vaccine's contribution to Gulf War illnesses has simply not been done.

Could the smokescreen be deliberate? The Office of the Secretary of Defense contracted with the RAND Corp. to produce eight volumes on various Gulf War illness exposures. Since 2000, only one has remained unavailable: the study of vaccines and Gulf War illnesses. Dr. Beatrice Golomb completed this report in 1999, but it was not published. At DoD direction she revised the report in 2004–5, and for a time the RAND website promised publication in 2005, but it still remains unpublished.[15] Neither DoD nor RAND has explained why.

Even the journal Science commented on the perceived lack of objective science in Gulf War illness research:

"Questions about the Pentagon's ability to objectively study Gulf War illness have dogged the department for years and spawned numerous conspiracy theories. Removing those doubts has proven difficult. Just 6 weeks ago, an independent panel reported that the Pentagon had worked "diligently . . . to leave no stone unturned." But that conclusion was spoiled by nasty disputes among panel members and staff, some of whom charge that its review was flawed and anything but independent." [16]

What do we know about anthrax vaccine and adverse health effects?

There are two diametrically opposed bodies of work on this subject. Studies performed by the Defense Department since 1998 have uniformly found the anthrax vaccine to be safe, as did one Institute of Medicine (IOM) Committee funded by the Defense Department. However, that Committee chose to ignore all anthrax vaccine-related studies of Gulf War illnesses,[17] and also failed to use the traditional weight-of-evidence approach.[18] The DoD studies are filled with methodological errors, as outlined by FDA in the vaccine label.[19] Yet it was these studies that formed the primary basis for the 2002 IOM report used by DoD to validate the vaccine's safety.

Because the U.S. Army developed the anthrax vaccine, owns the patent, owns the production equipment, owns most of the vaccine stockpile, has indemnified the vaccine manufacturer against all claims regarding lack of safety or efficacy, and chose to vaccinate its troops with an insufficiently tested and improperly licensed vaccine [20] on a mandatory basis, it is potentially at risk for large financial losses if the

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[14] VA Research Advisory Committee on Gulf War Veterans' Illnesses. Scientific Progress in Understanding Gulf War Veterans' Illnesses: Report and Recommendations. September 2004. www1.va.gov/rac-gwvi/docs/Report and Recommendations_2004.pdf

[15] http://www.rand.org/multi/gulfwar/publications.html

[16] Enserink M. Medicine: Restoring Faith in the Pentagon. Science 2001;291(5505):816.

[17] from Chapter 4: "The Committee did not include various studies that sought to identify risk factors for the health problems reported by some Gulf War veterans." Committee to Assess the Safety and Efficacy of the Anthrax Vaccine. Medical Follow-Up Agency, Institute of Medicine. Anthrax Vaccine: Is it Safe? Does it Work? National Academy Press 2002; Washington, DC.

[18] Ibid. Committee to Assess the Safety and Efficacy of the Anthrax Vaccine. Medical Follow Agency, Institute of Medicine. Anthrax Vaccine: Is it Safe? Does it Work? National Academy Press 2002; Washington, DC. From Chapter 1: "Several previous IOM Committees evaluating possible causal associations between vaccines or other exposures and specific health outcomes have chosen to describe their findings with a weight-of-evidence approach (IOM, 1991, 1994, 2000b). . . . The current committee chose not to use that approach because it was not asked to evaluate exposure to AVA as a cause of specific health outcomes. Rather, the Committee was asked to provide an overall evaluation of the anthrax vaccine's safety."

[19] http://www.fda.gov/OHRMS/DOCKETS/98fr/05n-0040-bkg0001.pdf

FDA criticized these studies' methodologies in the vaccine label, stating: "In addition to the VAERS data, adverse events following anthrax vaccination have been assessed in survey studies conducted by the Department of Defense in the context of their anthrax vaccination program. These survey studies are subject to several methodological limitations, e.g., sample size, the limited ability to detect adverse events, observational bias, loss to follow-up, exemption of vaccine recipients with previous adverse events and the absence of unvaccinated control groups."

[20] The vaccine license was pulled by Federal Judge Emmett Sullivan of the 1st District Court in December 2003 and October 2004 for failures in the licensing process. FDA subsequently

vaccine is found to be dangerous, its production negligent, or if the vaccine stockpile cannot be used. (One case of a disabled civilian Merchant Mariner, vaccinated with anthrax and smallpox vaccines, was settled for 2 million dollars.)[21]

The non-DoD studies suggest the anthrax vaccine was a contributor to Gulf War illnesses, and a cause of multiple chronic medical problems. These studies include one by Unwin et al., which found British anthrax vaccinations to have increased the risk of chronic Gulf War illnesses by 50% in Gulf War veterans, and by 230% in a small cohort of vaccinated Bosnia veterans.[22] The Canadian Department of National Defense hired a contractor to investigate Gulf War exposures and subsequent illnesses. Anthrax vaccine recipients had a 92% greater chance of developing chronic fatigue than unvaccinated veterans.[23] A DoD–HHS Anthrax Vaccine Expert Committee found that combinations of symptoms suggestive of Gulf War illnesses reported to the FDA–CDC's Vaccine Adverse Event Reporting System (VAERS) occurred 2–3 times as often as would have been expected by chance alone.[24] Females have had higher rates of Gulf War illnesses than male veterans; females also have two times the rate of immediate systemic adverse reactions to anthrax vaccine as males, and file reports to VAERS at 3 times the rate of males. Schumm[25] and Wolfe[26] both determined that anthrax vaccine was a risk factor for Gulf War illness in separate cohorts of veterans.

As of June 26, 2007, the Vaccine Adverse Event Reporting System had received a total of 5359 adverse event reports for anthrax vaccine. These included 670 reports that FDA had designated serious, and 44 reports of deaths.[27]

Raw data from the military's Defense Medical Surveillance System in 2001[28] revealed statistically significant increased rates of hospitalizations after vaccination, compared to pre-vaccination, for heart attacks, psychosis, depression, breast cancer, thyroid cancer, gallbladder and bile duct cancers, uterine cancer, diabetes, blood clots, asthma, multiple sclerosis and abnormal PAP smears in 300,000 soldiers. Yet no focused studies of these relationships have been conducted or made public since.

An unpublished Navy study of active duty women inadvertently vaccinated during the first trimester, revealed a 39% greater rate of birth defects in vaccinated mothers, compared to mothers who received anthrax vaccine at any other time.[29] An Army study found no increased rate of birth defects in vaccinated mothers, but did not examine first trimester vaccinations, and was admittedly not adequately powered to examine the issue.[30]

Easily verifiable, but non-public, DoD and CDC data suggest that anthrax vaccine is associated with birth defects and long-term adverse effects. Just last month the GAO, citing CDC and Vaccine Healthcare Center officials as sources, reporting that 1–2% of anthrax-vaccinated individuals "may experience severe adverse events,

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issued a Final Rule and a comment period, reestablishing the license, but new litigation was filed in December 2006 challenging the license on the basis of inadequate safety and efficacy data.

[21] Francis v. Maersk Line Limited and United States of America. Case No. C03–2898C. U.S. Dist Ct. for the Western District of Washington, ruling by Judge John C. Coughenour, Dec 9, 2005 to deny Def. motion to deny admissibility of Plaintiff expert witness

[22] Unwin C, Blatchley N, Coker W, Ferry S, Hotopf M, Hull L, et al. Health of UK servicemen who served in Persian Gulf War. Lancet. 1999 Jan 16; 353(9148):169–78.

[23] Goss-Gilroy. Study of Canadian Gulf War Veterans: NR–98.050. Study contracted by the Canadian Department of National Defense, released June 29, 1998 and published on its website, accessed between 1999 and 2001 but no longer at the previous URL: http://www.dnd.ca/menu/press/Reports/Health/health_study_eng_1.htm.

[24] Sever JL, Brenner AI, Gale AD et al. Safety of anthrax vaccine: an expanded review and evaluation of adverse events reported to the Vaccine Adverse Event Reporting System (VAERS). Pharmacoepidemiology and Drug Safety 2004; 13: 825–840.

[25] Schumm WR, Jurich AP, Bollman SR et al. The long term safety of anthrax vaccine, pyridostigmine bromide tablets, and other risk factors among Reserve Component Veterans of the First Persian Gulf War. Medical Veritas 2005;2:348–362.

[26] Wolfe J, Proctor SP, Erickson DJ, Hu H. Risk factors for multisymptom illness in U.S. Army veterans of the Gulf War. J Occup Environ Med. 2002 Mar; 44(3):271–81.

[27] Copies of the serious VAERS reports and all VAERS reports were obtained by FOIA and uploaded to my website: http://www.anthraxvaccine.org/serious_VAERS_reports.pdf and http://anthraxvaccine.org/all_VAERS_reports.pdf

[28] Presented to the Committee to Assess the Safety and Efficacy of the Anthrax Vaccine. Medical Follow-up Agency, Institute of Medicine. Washington, DC. 2001. Can be accessed in the IOM reading room. 4 tables are published in Appendix G of the IOM report (cited in footnote 17) provide some of this data. I have uploaded some of the raw data tables for public access at the following locations: http://merylnass.googlepages.com/AMSAtitlepage.pdf http://merylnass.google pages.com/AMSASurveillanceofadverseeffectsofAV.pdf http://merylnass.google pages.com/IOMMentalDisorders.pdf

[29] http://www.anthrax.osd.mil/resource/qna/qaAll.asp?cID=312

[30] Wiesen AR, Littell CT. Relationship between pre-pregnancy anthrax vaccination and pregnancy and birth outcomes among U.S. Army women. JAMA 2002; 287

which could result in disability or death."[31] Since the CDC has been conducting a trial of anthrax vaccine in 1564 subjects since 2002, and the Vaccine Healthcare Centers have performed full evaluations on over 2,400 putative vaccine injuries, most following anthrax vaccinations, officials of these agencies should be knowledgeable about the effects of the vaccine. However, no published studies exist to confirm that 1–2% of vaccine recipients have serious or life-threatening adverse events, and the true number may be more or less than this. The number of deaths that were definitely caused by the vaccine is also unknown.

The evidence is convincing that anthrax vaccine is a contributor, but not the only contributor, to Gulf War illnesses.

How many individuals may be affected?

It is uncertain how many deployed Gulf War and non-deployed Gulf "era" veterans received this vaccine. The Pentagon estimated that 150,000 deployed 1991 Gulf War veterans received anthrax vaccine. The VA Research Advisory Committee on Gulf War Veterans' Illnesses staff, using the 40% anthrax vaccination rate in self-reports, estimated that 285,000 veterans received anthrax vaccine in the Gulf War period.[32] Reports exist of experimental anthrax vaccines that were used in addition to the licensed vaccine.[33] There are very few available records of who received any anthrax vaccines in theater during Operations Desert Shield and Desert Storm. (Yet the Pentagon did a study in over 400 Fort Bragg soldiers 2 years after the war, in which booster doses of anthrax and botulinum toxoid vaccine were administered. The Pentagon was somehow able to identify the number of anthrax and botulinum toxoid vaccines administered during the subjects' Gulf War deployment, and the dates, for all soldiers in the study.[34])

Subsequent to the Gulf War, FDA estimated that 475,000 soldiers received anthrax vaccine between 1991 and 1998, yet very few veterans have anthrax vaccine listed in their medical records from this period.[35] Since 1998, 1.6 million soldiers have received anthrax vaccinations, averaging 4 doses each. An unknown number of military contractors and merchant mariners have also received anthrax vaccinations.

Thus over two million American soldiers have been vaccinated since the 1991 Gulf War, half of whom have been vaccinated since the start of Operation Iraqi Freedom. Consequently, DVA may continue to see large numbers of veterans who have become ill as a result.

How can DVA improve its research and its care of ill Gulf War veterans?

1. DVA has the ability to conduct the long-term anthrax vaccine safety studies, and should do so, as advised by every expert Committee that has investigated the vaccine.[36] Matched vaccinated and unvaccinated cohorts could be studied longitudinally to finally resolve questions about the types and rates of illness associated with the vaccine.
2. DVA should support the Research Advisory Committee on Gulf War Veterans' Illnesses recommendations regarding areas of research that are likely to bear fruit. Clinical research intended to improve the treatment of veterans should receive the highest priority.
3. DVA should improve its ability to provide care to veterans with Gulf War illnesses and vaccine-associated illnesses. DVA designated physicians at each facility to care for Gulf War veterans, but the level of support and training provided to these physicians has not been adequate. Although DVA has convened consensus panels and created clinical algorithms for its practitioners, the fact remains that to effectively evaluate and treat these patients is extremely difficult. The patients often have idiosyncratic responses to medications, particularly if they are chemically sensitive. They may react adversely to odors in the clinic. They usually have cognitive and often emotional problems, and often for-

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[31] GAO–07–787R. Military Health: DoD's Vaccine Healthcare Centers Network. June 29, 2007. http://www.gao.gov/cgi-bin/getrpt?GAO-07-787R

[32] LaClair B. Overview of exposures and health conditions reported by countries who served in the 1990–1991 Gulf War allied coalition. Presentation to the Department of Veterans' Affairs Research Advisory Committee on Gulf War Veterans' Illnesses. December 12–13, 2005. Washington, DC.

[33] Takafuji ET and Russell PK. Military immunizations. Past, present and future prospects. Infect Dis Clin North Am 1990; 4(1):143–58.

[34] Pittman PR, Hack D, Mangiafico J et al. Antibody response to a delayed booster dose of anthrax vaccine and botulinum toxoid. Vaccine 2002; 20(16):2107–15.

[35] Clifford J (FDA). Statement to the Institute of Medicine Committee on anthrax vaccine safety and efficacy. October 3, 2000.

[36] Compilation of expert Committee recommendations: http://www.anthraxvaccine.org/every.htm

get their doctor's advice. They require a very patient and understanding clinician, and need detailed written instructions to take home. These patients require care from multiple medical specialists and therapists, and their primary provider needs to supervise this process. They have more symptoms, and require much longer visits, than other patients.

Ideally, DVA will follow the model that DoD and CDC, under Congressional directives, pioneered. DoD and CDC jointly created a Vaccine Healthcare Centers Network of four clinics, which perform very detailed and complete evaluations of patients. This provides a solid basis for treating complex patients by establishing firm diagnoses, and furthermore allows for a strong bond to develop between the patient and the provider. This bond is particularly important for the patients, whose condition is likely to be poorly understood by other providers, and who may have lost trust in the military and DVA systems.

DoD also created a Deployment Health Center at Walter Reed, where a similar detailed diagnostic process can take place, and patients undergo inpatient training about their condition and how best to manage it. This type of center might also be beneficial for Gulf War illness and vaccine-injured patients.

4. Treatment trials for those with Gulf War illnesses are sorely needed. For example, many Gulf War veterans have chronic diarrhea. Empiric trials that included antibiotics, anti-yeast drugs, dietary manipulation, digestive enzymes and probiotics such as Lactobacillus rhamnosus could be done in conjunction with studies of motility, stool flora, and autonomic nervous system dysfunction. Veterans should be screened for hypogonadism, and offered replacement hormone if positive. Those with sleep disorders should undergo formal sleep studies and be given C–PAP trials as indicated. A specialty Gulf War clinic could make such evaluations routine.
5. Accurate, linked medical records between DoD and DVA are a prerequisite for optimal care of veterans. According to GAO, "In 1997, the President, responding to deficiencies in DoD's and VA's data capabilities for handling service members' health information, called for the two agencies to start developing a comprehensive, lifelong medical record for each service member."[37] Yet the databases are still not linked. Congressional attention to this issue might generate more progress than has been made in the 10 years since this policy was put in place.
6. DoD and DVA receive entirely separate funding. Thus, the Defense Department does not have to pay for the long-term care required by soldiers who become ill as a result of DoD's medical countermeasures. Ill soldiers are medically discharged, and costs are shifted to the DVA.

   If DoD was required to contribute to the long-term care of some ill soldiers, it might place a higher priority on the safety of the countermeasures and other exposures to which its troops are subjected. Congress should consider instituting a mechanism that would extract a financial penalty from the Pentagon when its decisions lead to high rates of (preventable) chronic medical illnesses in its soldiers.
7. A huge amount of effort and money was expended to research Gulf War illnesses for very little return. After arranging for 300 studies, it is striking that DVA and DoD have not published quality reviews of this body of work, which would make an understanding of the subject so much easier for the public. The officials in charge of this failed research project have, for the most part, remained in control for the past 10 years. Congress must assure accountability by insuring that future funding of Gulf War illness research is conducted objectively, and is independent of the institutional biases so far demonstrated by DoD and DVA.

Prepared Statement of James Binns, Chairman, Research Advisory Committee on Gulf War Veterans' Illnesses, U.S. Department of Veterans Affairs

Mr. Chairman, Members of the Committee, for the past 5 years, it has been my privilege to chair the Research Advisory Committee on Gulf War Veterans Illnesses. This public advisory body of distinguished scientists and veterans is mandated by

[37] GAO–02–478T. VA and Defense Health Care. Military Medical Surveillance Policies in Place, but Implementation Challenges Remain. February 27, 2002.

Congress and appointed by the Secretary of Veterans Affairs. Its membership includes leading experts in the field, a former president of the American Academy for the Advancement of Science, and the head of the CDC Neurotoxicology Research Laboratory. Dr. Steele (to my right) is a member and an epidemiologist who has devoted the past 10 years of her career to the full time study of Gulf War illnesses, most recently as scientific director of the Committee. The Committee's statutory mission is to review research studies and plans related to the illnesses suffered by veterans of the 1991 Gulf War.

Dr. Steele will provide highlights of the Committee's scientific findings. I will address the status of Federal research activities.

Gulf War illnesses remain a major unmet veterans' health problem. According to the Department of Veterans Affairs most recent study, 25% of Gulf War veterans suffer from chronic multisymptom illness over and above the rate in other veterans of the same era. This confirms five earlier studies showing similar rates.

Thus, 16 years after the war, one in four of those who served—175,000 veterans—remain seriously ill. And there are currently no effective treatments.

Gulf War veterans also suffer from amyotrophic lateral sclerosis, ALS, at double the rate of other veterans of the same era.

The veterans whom you have heard today are not exceptional cases. They are representative casualties of the 1991 Gulf War.

The Federal Government has spent over $300 million on Gulf War illnesses research, roughly one-third by VA and two-thirds by DoD. Some of that research was productive, as you will hear from Dr. Steele. Much of that money, however, was misspent on the false theory that these illnesses were caused by psychological stress. As late as 2003, 57% of new VA Gulf War illnesses research was directed at psychological stress.

This emphasis on stress was part of an overall effort to portray these illnesses as nothing unusual, the kind of thing that happens after every war, rather than the result of toxic exposures particular to the Gulf War. Very little money was invested in treatment research.

I am pleased to report that a dramatic change for the better has taken place in the direction of VA research. Following our Committee's 2004 report, then VA Secretary Principi announced that VA would no longer fund studies based on stress. Secretary Nicholson appointed new leadership at the VA Office of Research and Development, and has placed most of VA's Gulf War illnesses research program at the University of Texas, Southwestern Medical Center, the leading site for Gulf War illnesses research. Congress added $15 million to the VA research budget for this program, which is just getting underway. I am extremely pleased to see VA Gulf War illnesses research in the hands of scientists committed to solving the problem and fully funded at the level recommended by the Research Advisory Committee.

At the same time that these positive developments have taken place, however, other key VA officials continue to minimize these illnesses at every opportunity. For example, a "fact sheet" provided in recent weeks to three U.S. Senators baldly asserted that "Gulf War veterans suffer from a wide range of common illnesses, which might be expected in any group of veterans their age." That is utter hogwash.

This fact sheet is the work of the VA Office of Public Health and Environmental Hazards, which is testifying before you today. It is also the VA office charged with implementing Congress's mandate that VA contract with the National Academy of Sciences' Institute of Medicine to prepare reports on the association between toxic exposures in the Gulf War and health effects for use in benefits determinations. For 7 years, these reports have been structured to restrict the scientific information considered in their conclusions, in express violation of the statute.

This government manipulation of science and violation of law to devalue the health problems of ill veterans is something I would not have believed possible in the United States of America until I took this job. Until this practice is stopped, the products of Gulf War illnesses research will be distorted, misleading the Secretary, Congress, veterans' doctors, and the scientific community.

Dr. Lawrence Deyton, who now directs this office and who will speak to you later this morning, assumed his position relatively recently and did not initiate these practices. I urge Dr. Deyton to order these misleading activities terminated and previous IOM reports re-done in conformity with the statute.

The largest sponsor of Federal Gulf War illnesses research is the Department of Defense. Historically, DoD has funded approximately two-thirds of Gulf War illnesses research, in excess of $30 million annually. Since the start of the current war, however, this program has been eliminated.

In FY06, Congress initiated a new pilot program for Gulf War illnesses research at DoD. This innovative program gives first priority to pilot studies of existing treatments already approved for other illnesses, and so offers the possibility of identi-

fying treatments that could be put to immediate use. It complements the VA/University of Texas research program that is focused on understanding the basic science. It is open to all researchers, inside or outside of government, through peer-reviewed competition, and is administered by the Congressionally Directed Medical Research Program.

Its initial solicitation last fall received eighty proposals—compared to only two treatments studied in the entire previous history of Gulf War illnesses research. Only a small fraction of these proposals can be funded within the $5 million FY06 pilot program, but the response demonstrates the interest of the scientific community in finding treatments to improve the health of Gulf War veterans, as well as current and future military personnel and civilians at risk of chemical attack.

Yet DoD has again excluded this promising program from its proposed FY08 budget. Its future depends on the success of bipartisan efforts in the House and Senate to add it to the DoD budget at the $30 million level consistent with the recommendations of the Research Advisory Committee and historic funding commitments.

Mr. Chairman and Members of the Committee, in recent months this country has renewed its obligation to care for the health of veterans following their return home from war. Hundreds of millions of dollars have been appropriated to address the health problems of currently returning veterans, and rightfully so. But it is now time—in fact, long past time—to address the serious health problems of 175,000 veterans of the last war who remain ill as a result of their service.

Will we follow the example of the current war and address them now, while there is still hope they can live out their lives in better health? Or will we follow the example of Vietnam and Agent Orange, and admit the problem only as they are dying? The answer begins with you and your colleagues.

Prepared Statement of Lea Steele, Ph.D., Scientific Director, Research Advisory Committee on Gulf War Veterans' Illnesses, U.S. Department of Veterans Affairs, and Associate Professor, Kansas State University

Good morning and thank you for inviting me here today. I'm Dr. Lea Steele, an epidemiologist and associate professor at Kansas State University. I first became involved in Gulf War research 10 years ago when I directed a state-sponsored research and service program for Gulf War veterans in Kansas. Our work there provided important insights about Gulf War illness. I am now "on loan" from my university to the Federal Government to serve as Scientific Director of the Federal Research Advisory Committee on Gulf War Veterans' Illnesses. Our Committee has reviewed and analyzed a vast amount of scientific research and government investigative reports that provide extensive information on the Gulf War and the health of Gulf War veterans. We will be issuing our scientific findings and recommendations in a major report to be released later in the year. My purpose today is to share with you some highlights of what the Committee has learned in the course of our scientific work.

First, I want to distinguish between the condition known as Gulf War illness and other health issues related to the 1991 Gulf War. Gulf War illness is a complex of symptoms found at high rates in Gulf War veterans-an illness not explained by standard diagnoses and medical tests. This symptom complex affects Gulf War veterans from different units across the U.S. and also from some allied countries. It affects more Gulf War veterans, by far, than any other identified health condition.

There are also other health issues related to Gulf War service. A problem of great concern is ALS, as you've heard. According to a large VA study, ALS affects twice as many Gulf War veterans as other veterans of that period. This neurodegenerative disease usually strikes people over age 55, but one study has reported that Gulf War veterans may develop ALS at much younger ages. A more recent study has suggested that those who have served in the military, in general, are at increased risk for ALS. If true, this could raise even greater concerns, since Gulf War veterans have ALS at twice the rate of other military veterans.

Brain cancer has also been recently identified as a Gulf War health issue. You may be familiar with a well-known incident near Khamisiyah, Iraq, in March 1991. The Pentagon has estimated that about 100,000 U.S. military personnel were potentially exposed to low-level nerve agents in connection with demolitions at a large weapons depot that contained sarin and cyclosarin. A 2005 study found that veterans who were downwind from those demolitions have died from brain cancer at twice the rate of veterans in other areas of theater.

There might also be problems related to other diagnosed diseases, but studies are lacking. The Research Advisory Committee has recommended research to assess conditions such as multiple sclerosis, Parkinson's diseases, and cancer in Gulf War veterans. While all of these issues are important, far fewer Gulf War veterans have ALS or brain cancer than the very large number affected by Gulf War illness. So I will focus my scientific comments today on what we know about Gulf War illness.

First, let me briefly describe what Gulf War illness looks like, in case you don't have a complete picture from veterans who have testified or whom you know personally. Veterans with Gulf War illness have multiple, persistent symptoms that affect different body systems. These include neurological-type problems—severe headaches, memory and concentration problems, dizziness, and mood changes. Persistent and widespread pain is also a prominent feature of Gulf War illness, as well as a profound fatigue. Other troubling symptoms include gastrointestinal problems—we know many veterans have had persistent diarrhea for 15 years. Respiratory symptoms—coughing and wheezing—are also common, as well as unusual skin lesions and rashes. Veterans with Gulf War illness experience multiple different types of symptoms together, which is why we call it a symptom complex or multisymptom illness. We now know quite a lot about Gulf War illness-how many veterans are sick, who is most affected, and what may have caused this condition. Here are some of the highlights.

- **Gulf War illness is a big problem.**
  25–30 percent of veterans who served in the Gulf War are affected by this complex of symptoms as a consequence of their Gulf War service. This has been shown by multiple studies, including VA's most recent large follow-up study. That means that Gulf War illness affects between 175,000 and 200,000 of the 700,000 Americans who served in the Gulf War.
- **Gulf War illness was not caused by psychological stress.**
  Comprehensive studies have found no connection between Gulf War illness and combat experiences in the war. In fact, rates of psychiatric conditions like PTSD are considerably lower in Gulf War veterans than veterans of other wars. This stands to reason since, in contrast to current deployments, severe stress and trauma were relatively uncommon in the 1991 Gulf War. A decisive victory was achieved after a 4 day ground war; most troops did not see combat and were never even in areas where battles occurred.
- **Research studies consistently identify links between Gulf War illness and neurotoxic chemicals.**
  Many different Gulf War exposures have been suggested as causes or contributors to Gulf War illness. These include the smoke from over 600 burning Kuwaiti oil wells, receipt of numerous military vaccines, depleted uranium munitions, and low-dose exposure to chemical weapons.
  The most consistent and extensive amount of available evidence implicates a group of chemicals to which veterans were exposed that can have toxic effects on the brain. These chemicals include pills (NAPP pills or pyridostigmine) given to protect troops from the effects of nerve agents, excessive use of pesticides, and low levels of nerve gas in theater. Many of these chemicals have a similar type of action; they adversely affect the neurotransmitter acetylcholine. Studies also show that these chemical toxins can act synergistically, that is, combined exposures are worse than any single exposure by itself.
  A link between Gulf War illness and exposure to neurotoxic chemicals is also compatible with what we know about biological processes affecting ill veterans. Diverse studies have identified abnormalities in the brain and the autonomic nervous systems of sick Gulf War veterans. Diverse types of brain scans and neurocognitive tests have identified problems that affect different brain processes and areas. For example, in recent months, news stories have widely reported on studies showing that Gulf War veterans have reduced volume in specific brain regions.
- **Effective treatments for Gulf War illness are urgently needed.**
  Studies show that few veterans with Gulf War illness have recovered or even substantially improved over time. As a result, many Gulf War veterans have been sick for as long as 16 years. Effective treatments for Gulf War illness have not been identified—very few have even been studied. The Research Advisory Committee continues to identify research that can lead to treatments that improve the health of ill Gulf War veterans as the highest priority area of Gulf War research.

In short, Gulf War illness is real, it is serious, and it is still widespread among veterans of the 1991 Gulf War. It is not the result of psychological stress and is not the same thing that happens after every war. Progress has been made in under-

standing "big picture" questions about Gulf War illness and health issues affecting Gulf War veterans. The Research Advisory Committee believes that remaining important questions can also be answered and must be addressed. The Federal Government has a continuing obligation to attend to the health problems affecting veterans of the 1990–1991 Gulf War. Further, a more complete understanding of Gulf War illness is required to ensure that similar problems do not affect future American troops deployed to war.

Prepared Statement of Lawrence Deyton, MSPH, M.D., Chief Public Health and Environmental Hazards Officer, Veterans Health Administration, U.S. Department of Veterans Affairs

Mr. Chairman and Members of the Subcommittee, thank you for providing the Department of Veterans Affairs (VA) this opportunity to discuss VA's response to the health care and other needs of veterans who have served in combat in Southwest Asia. With me today is

- Mark Brown, PhD, Director, Environmental Agents Service, Office of Public Health and Environmental Hazards
- Timothy O'Leary, Director, Biomedical Laboratory Research and Development Service, Director, Clinical Science Research and Development Service, Office of Research and Development and
- Eugene Oddone, MD, MHSc, Director, Center for Health Services Research in Primary Care and Principal Investigator, National Registry of Veterans with ALS

My testimony today will address three major topics: (1) VA's efforts toward improving clinical care and our understanding for the illnesses affecting veterans who served in the 1991 Gulf War, (2) how these efforts have helped us in responding to the health care and other needs of our troops fighting in this same region today; and (3) VA's response to concerns about potential increased risk of Amyotrophic Lateral Sclerosis (ALS, or "Lou Gehrig's Disease) among military service members.

BACKGROUND

The United States deployed nearly 700,000 military personnel to the Kuwaiti Theater of Operations (KTO) during Operations Desert Shield and Desert Storm (August 2, 1990, through July 31, 1991). Within months of their return, some Gulf War veterans reported various symptoms and illnesses that they believed were related to their service. Veterans, their families, and VA subsequently became concerned about the possible adverse health effects from various environmental exposures during Operations Desert Shield and Desert Storm.

Of particular concern have been the symptoms and illnesses that, to date, have eluded specific diagnosis. More than 130,000 Gulf War veterans have participated in the two health registries that VA and the Department of Defense (DoD) maintain. In addition, more than 335,000 have been seen at least once as patients by VA. *Although the majority of veterans seeking VA health care had readily diagnosable health conditions, we remain very concerned about the veterans whose symptoms could not be diagnosed.*

I would like to provide a brief description of some of the programs and initiatives VA developed in response to health concerns of veterans of the 1991 Gulf War. I will also focus on how these new programs have benefited the veterans who are now returning from the current conflicts in Southwest Asia, specifically veterans from Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) and their families.

VA INITIATIVES FOR SOUTHWEST ASIA COMBAT VETERANS

The VA Gulf War Veteran Health Registry. Even before the 1991 Gulf War cease-fire VA had concerns that returning veterans might have certain unique health problems including respiratory effects from exposure to the intense oil fire smoke.

In response, VA quickly established a clinical registry to screen for this possibility. The new voluntary health registry examination also helped encourage new combat veterans to take advantage of VA health care programs. VA has long maintained health registries on other at-risk populations, including veterans exposed to radiation, and Vietnam veterans exposed to Agent Orange.

Formally established by law in 1992, VA's Gulf War Veterans' Health Examination Registry is still available to all Gulf War veterans, including veterans of the

current conflict in Iraq. It offers a comprehensive physical examination, and collects data from participating veterans about their symptoms, diagnoses, and self reported Gulf War hazardous exposures. As of June 2007, this program evaluated over 100,000 Gulf War veterans, or about 1 in 7 veterans.

The program has also seen nearly 7,000 veterans who served in the current conflict in Iraq, who as Gulf War veterans themselves, are eligible for this program.

After 15 years, the principal finding from VA's systematic clinical registry examination of about 14 percent 1991 Gulf War veterans is that they are suffering from a wide variety of common, recognized illnesses. However, no new or unique syndrome has been identified. Registry data has significant limitations. VA recognizes that in the long run, establishing high quality epidemiological research studies is the best approach for evaluating the health impacts of service in the 1991 Gulf War (or in any deployment). VA has adopted that approach.

New Compensation for Undiagnosed Illnesses. Many new Gulf War veterans encountered problems when they tried to prove that their difficult-to-diagnose or undiagnosed illnesses were connected to their military service. This affected their access to disability compensation. In response, VA asked Congress for authority, granted under Public Law 103–446, to provide compensation benefits to Gulf War veterans who are chronically disabled by undiagnosed illnesses when certain conditions are met. This statute as amended authorizes VA to pay compensation for disabilities that cannot be diagnosed as a specific disease or injury, or for certain illnesses with unknown cause including chronic fatigue syndrome, fibromyalgia and irritable bowel syndrome.

Symptoms potentially covered include 1) fatigue; 2) skin signs or symptoms, including hair loss; 3) headache; 4) muscle pain; 5) joint pain; 6) neurologic signs or symptoms; 7) neuropsychological signs and symptoms, including memory loss; 8) signs or symptoms involving the respiratory system; 9) sleep disturbances; 10) gastrointestinal signs or symptoms; 11) cardiovascular signs and symptoms; 12) abnormal weight loss; and 13) menstrual disorders. This is a unique benefit for Gulf War veterans, and more than 3,300 have received service connection for their undiagnosed or difficult to diagnose illnesses under this authority. Veterans from the current conflict in Iraq are also eligible for this special benefit.

Epidemiological Research on Gulf War Veterans. Despite the value of VA's Gulf War Health Registry program, additional epidemiological research is required to properly characterize any possible long-term health effects of Gulf War 1 service to the average Gulf War veteran. This is because the registry participants are self-selected, and therefore do not represent the average veteran. Registry findings demonstrate that Gulf War veterans are not showing up with any unique health problems; however, these findings do not tell us if veterans are suffering from any diagnoses at rates different from expected. That requires population-based epidemiological and related research studies, which VA has carried out.

VA Gulf War Veteran Mortality Study. VA researchers have been continuously monitoring the cause-specific mortality of all Gulf War veterans in comparison to their non-deployed peers. In post-war monitoring, Gulf War veteran mortality from most causes is not significantly different in comparison to non-deployed peer as controls. Moreover, the mortality for both groups is less than half that of matched civilian controls. This is almost certainly because people who choose to go into the military are healthier to begin with.

Initially, Gulf War veterans have shown an increased risk of death from accidents, especially motor vehicle accidents. VA's data shows that this is a temporary effect, and by 6 years post-war this difference has disappeared. This overall pattern is very consistent with earlier mortality data from Vietnam veterans.

New Clinical Guidelines for Combat Veteran Health Care. Early on, VA recognized the need to assure training of our health care providers to allow them to best respond to the specific health care needs of Gulf War veterans with difficult-to-diagnose illnesses. With that in mind, and in collaboration with the Department of Defense (DoD), VA developed two Clinical Practice Guidelines on combat veteran health issues. This included a general guideline on post combat deployment health, and a second dealing with diagnosis of unexplained pain and fatigue. These clinical guidelines give VA health care providers access to the best medical evidence for diagnoses and treatment. Developed in response to veterans of the 1991 Gulf War, today VA highly recommends these for the evaluation and care of all returning combat veterans, including veterans from OEF and OIF. (also available online at www.va.gov/EnvironAgents)

New VA "War-Related Illness & Injury Study Centers:" Specialized Health Care for Combat Veterans. In 2001, as part of VA's overall health response for veterans returning from the 1991 Gulf War, VA established two War Related Illness and Injury Study Centers (WRIISCs), at the Washington, DC, and East Orange, NJ

VA Medical Centers (VAMCs). Today, these two centers are providing specialized health care for combat veterans from all deployments who experience difficult to diagnose or undiagnosed but disabling illnesses. VA now anticipates concerns about unexplained illness after virtually all deployments including OEF and OIF, and we are building on our understanding of such illnesses.

Currently, VA is expanding on this program to better meet the health care needs of new combat veterans suffering from mild to moderate traumatic brain injury. To that end, VA is establishing a third WRIISC at the Palo Alto VA Health Care System. This will take advantage of their unique assets including a Polytrauma Unit, interdisciplinary program on blast injuries which integrates the medical, psychological, rehabilitation, prosthetic needs of injured service members, their programs in traumatic brain injury, spinal cord injury, blind rehabilitation post traumatic stress disorder, and research into new and emerging areas of combat injuries and illnesses. This is a critical development because combat injuries we see today among OEF and OIF veterans are much more likely, compared to previous wars, to involve some degree of traumatic brain injury. This has been the result of the types of weapons commonly used to attack our troops, including improvised explosive devices, blasts from landmines, artillery and mortar attacks, and the resulting shrapnel produced from such devices. Many of the long-term chronic health effects from traumatic brain injury appear similar to the difficult-to-diagnose and treat illnesses currently being treated by the WRIISC programs today.

Expanded Education on Combat Health Care for VA Providers. In response to health problems faced by veterans of the 1991 Gulf War, VA developed the Veterans Health Initiative (VHI) Independent Study Guides for health care providers titled, "A Guide to Gulf War Veterans Health." Although originally focusing on health care for combat veterans from the 1991 Gulf War, this study guide remains highly relevant for treating OEF and OIF combat veterans, since many of the hazardous deployment-related exposures are the same for both conflicts.

VA also developed several additional VHI Independent Study Guides and other materials relevant to veterans returning from Iraq and Afghanistan. These include the Under Secretary for Health Information Letter "Preparing for the Return of Women Veterans from Combat Theater," (IL 10–2003–011), which provides guidance on the special care needs for women OEF and OIF combat veterans.

Another VHI independent study guide in this series, "Endemic Infectious Diseases of Southwest Asia," provides guidance to health care providers about the infectious disease risks in Southwest Asia, particularly in Afghanistan and Iraq. The emphasis is on diseases not typically seen in North America.

Similarly, "Health Effects from Chemical, Biological and Radiological Weapons" was developed to improve recognition of health issues related to chemical, biological, and radiological weapons and agents.

The guideline, "Military Sexual Trauma," was developed to improve recognition and treatment of health problems related to military sexual trauma, including sexual assault and harassment.

Similarly, "Post-Traumatic Stress Disorder: Implications for Primary Care" is an introduction to PTSD diagnosis, treatment, referrals, support and education, as well as awareness and understanding of veterans who suffer from this illness.

"Traumatic Amputation and Prosthetics" includes information about patients who experience traumatic amputation during military service, their rehabilitation, primary and long-term care, and prosthetic clinical and administrative issues.

Finally, "Traumatic Brain Injury" presents an overview of TBI issues that primary care practitioners may encounter when providing care to veterans and active duty military personnel. All are available in print, CD ROM and on the web at www.va.gov/VHI.

VA National Training on Health Care for New Combat Veterans. Based on our experience treating veterans from the 1991 Gulf War, VA recognized the need to quickly familiarize all VA health care providers on the unique health concerns of new combat veterans returning from Iraq and Afghanistan. VA has sponsored multiple regional education conferences and a 3-day National Conference on "Providing Health Care for a New Generation of Combat Veterans Returning from OEF and OIF," in April 2007.

The conference objective was to sharpen the response of VA providers to new and transitioning combat veterans coming to us today, and to the new physical and behavioral health care challenges that these returning veterans bring with them. The meeting included plenary sessions featuring VA and DoD leadership, and breakout presentations from national and international experts describing their clinical and research experiences with new combat veterans.

Approximately 1,400 people attended this event, from throughout all of VHA. The target audience was VA primary care providers from around the country, including

social workers, psychologists and mental health professionals, physicians, physician assistants, nurses, and others who provide direct care to new combat veterans returning from Iraq and Afghanistan.

National subject matter experts from VA, DoD, and academia, presented their recent experiences responding to the health care needs of new combat veterans. The goal was to give VA healthcare professionals the tools they will need to respond to the unique and sometimes complex healthcare needs of returning combat veterans, and to develop the necessary competencies to provide optimal care. The deliberately multidisciplinary approach also helped providers to focus on more integrated health care delivery, foster networking. and share best practices, all of which should enable us collectively to improve outcomes for returning wounded service members.

Breakout session topics covered Polytrauma; Pain Management; Behavioral Health; Diversity Issues; Prosthetics; and Special Topics for New Combat Veterans.

Outreach to Combat Veterans and Their Families. VA has many programs designed to help returning combat veterans and their families. To help veterans of the 1991 Gulf War and their families be more aware of VA's health care and other benefits that are available for them, and of new research results on Gulf War veterans' health, VA initiated the "Gulf War Review" newsletter, which is regularly mailed out to over 400,000 veterans from that conflict.

VA has developed many new outreach and information products for new combat veterans and their families. The Secretary sends a letter to every newly separated OEF and OIF veteran, based on records for these veterans provided to VA by DoD. The letter thanks the veteran for their service, welcomes them home, and provides basic information about health care and other benefits provided by VA.

Similarly, in collaboration with DoD, VA published a new short brochure called "A Summary of VA Benefits for National Guard and Reservists Personnel." To date, over one million copies have been distributed. The new brochure summarizes health care and other benefits available to this special population of combat veterans upon their return to civilian life (also available online at www.va.gov/EnvironAgents). "Health Care and Assistance for U.S. Veterans of Operation Iraqi Freedom" is a new brochure on basic health issues for that deployment (also available online at www.va.gov/EnvironAgents).

Finally, VA started the "OEF and OIF Review," which is mailed to all separated OEF and OIF veterans (over 700,000 individuals as of July 2007) and their families, on VA health care and assistance programs for these newest veterans (also available online at www.va.gov/EnvironAgents).

Combat-Theater Veterans' Enhanced Access to VA Health Care. VA provides combat veterans enhanced enrollment placement and cost-free health care services and nursing home care for conditions possibly related to their service in a theater of combat operations after November 11, 1998 for a 2-year period beginning on the date of their separation from active military service. These veterans are placed into enrollment Priority Group 6 if not otherwise qualified for a higher enrollment Priority Group assignment and have full access to VA's Medical Benefit Package.

Veterans, including activated Reservists and members of the National Guard, are eligible if they served on active duty in a theater of combat operations during a period of war after the Gulf War or; were in combat against a hostile force during a period of "hostilities" after November 11, 1998 and, have been discharged under other than dishonorable conditions.

Veterans who enroll with VA under this authority retain enrollment eligibility even after their 2-year post discharge period ends under current enrollment policies. At the end of this 2-year period VA will reassess the combat veteran's information (including all applicable eligibility factors existing at this time) and make, as appropriate, a new Priority Group assignment.

Special Depleted Uranium (DU) Surveillance Program. Special armor piercing munitions and tank armor made from depleted uranium (DU) was used with great effect by U.S. forces during the 1991 Gulf War, as well as more recently during the initial phases of OEF and OIF. However, some veterans returning from these conflicts have had concerns that DU may have affected their health. In response, in 1993, VA established the DU Follow-up Program at the Baltimore VA Medical Center to monitor the health of veterans who had retained DU fragments in wounds—typically from "friendly fire" incidents in 1991 Gulf War. The program provides ongoing and thorough detailed physical examinations for affected veterans, including a broad array of testing of the blood, immune, reproductive, and central nervous systems, and of kidney and liver function.

In 1998, in response to increasing concerns among Gulf War veterans, this program was expanded to offer DU screening for *any* veteran concerned about possible DU exposure, and not just those with possible retained DU fragments or with other

types of high exposure risks. The program is also open for veterans who served in OEF and OIF.

Researchers with VA's DU Follow-up Program have not identified any clinically significant uranium-related health effects among veterans from exposure from inhalation or from retained DU fragments. There are however some concerns about certain physical changes that have been noted in imbedded DU fragments, and indications for surgical removal of fragments are currently under review by this group.

VA and DoD will continue to monitor health effects in this population, which includes both 1991 Gulf War veterans and veterans from the current conflict in Iraq.

New VA Toxic Embedded Fragments Surveillance Center. In response to health concerns for new OEF and OIF combat veterans suffering from retained embedded fragments composed of a wide range of metals and other materials as a result of blast injuries from improvised explosive devices, VA is establishing the Toxic Embedded Fragments Surveillance Center (TEFSC) at the Baltimore VA Medical Center. New studies indicate that some metals, such as certain tungsten alloy fragments, are highly carcinogenic in rats and may pose a health hazard in veterans. Some metals are also known or presumed to be human reproductive hazards, including lead, cadmium, nickel, and copper.

The Baltimore VA DU Surveillance Program has shown us that retained DU fragments and other materials are not necessarily inert in the body, and may change over time to produce potential toxic health effects. Such effects may be minimized and managed through careful ongoing medical surveillance.

New Combat Veteran Health Surveillance. The long-term epidemiological studies supported by VA assessing the health effects of the 1991 Gulf War on veterans who were deployed to Southwest Asia took a considerable amount of time. Today, we appreciate the importance of rapidly monitoring the health status of new combat veterans and have initiated surveillance and studies to more rapidly identify any health effects that may occur from this current conflict. This has been made possible via VA's electronic inpatient and outpatient medical records, which summarizes every single visit by a combat veteran including all medical diagnoses. For example, according to VA's July 2007 update "Analysis of VA Health Care Utilization among Southwest Asian War Veterans," since fiscal year (FY) 2002 over 700,000 OEF and OIF veterans have left active duty and become eligible for VA health care. About 35 percent of these new veterans (over 250,000) have received VA health care at least once since 2002.

This simple surveillance shows that new OEF and OIF veterans are coming to VA with a wide range of medical and psychological conditions. No special conditions stand out, and therefore these new combat veterans are being assessed individually to identify all their outstanding health problems. VA will continue to monitor the health status of recent OEF and OIF veterans using updated deployment lists provided by DoD to ensure that VA tailors its health care and disability programs to meet the needs of this newest generation of war veterans. Also using this new combat veteran roster, VA has developed a new clinical reminder in the electronic health record to assist VA primary care clinicians in providing timely and appropriate care to new combat veterans.

INDEPENDENT REVIEWS ON GULF WAR VETERANS' HEALTH

VA has sought advice on the health of combat veterans serving in Southwest Asia from a wide range of external advisory groups. For example, VA has long relied upon the independent scientific advice of the National Academy of Sciences (NAS) Institute of Medicine (IOM) to help evaluate potential associations between environmental hazards encountered during various military deployments and specific health effects. This external review process has resulted, for example, in VA recognizing about a dozen diseases as presumed to be connected to exposure to Agent Orange and other herbicides used during the Vietnam War, and to the dioxin impurity some contained.

The National Academy of Sciences was established in 1863 with the signature of President Abraham Lincoln, to "investigate, examine, experiment, and report upon any subject of science or art" for agencies in the Federal Government. In 1970, the NAS created the IOM to provide independent, objective, authoritative, credible and timely scientific analyses on medical and health issues.

The U.S. Congress, through U.S. Government agencies, regularly seeks the IOM's unique scientific advice on a broad range of health-policy issues. Their studies are conducted by independent Committees of volunteer scientists composed of leading nationally and internationally recognized experts, selected by the IOM based on their expertise, good judgment and freedom from conflict of interests. The IOM requires that a Committee's formal findings and recommendations are evidence-based whenever possible and noted as only expert opinion when that is not possible. Each

IOM report undergoes extensive formal internal and peer review by external experts who are anonymous to the Committee, and whose names are revealed only once the study is published.

Congressionally Mandated NAS/IOM Veterans' Health Reviews. The NAS/IOM's highly developed formal review process has proven invaluable to VA for establishing fair, scientifically based disability policies for veterans. Their reputation for objectivity, scientific integrity, and independence means that their reports stand as authoritative even when their findings fail to please all stakeholders. Since 1991, IOM has completed nineteen independent reviews of Gulf War health issues (see attachment). For evaluation of Gulf War-related health effects, Congress directed (in Public Laws 105–277 and 105–368) the NAS to "identify the biological, chemical, or other toxic agents, environmental or wartime hazards, or preventive medicines or vaccines to which members of the Armed Forces who served in the Southwest Asia theater of operations during the Persian Gulf War may have been exposed by reason of such service." Public Law 105–277 further required the NAS, for each substance or hazard considered, to determine, to the extent feasible, (1) whether a statistical association exists between exposure to the substance or hazard and the occurrence of illnesses, (2) the increased risk of the illness among exposed human or animal populations, and (3) whether a plausible biological mechanism or other evidence of a causal relationship between the exposure and illness exists.

VA RESPONSE TO PREVIOUS NAS COMMITTEE "GULF WAR & HEALTH" REPORTS

The 2000 Report. The initial 2000 NAS Committee report in this series, "Gulf War & Health Volume 1," reviewed health effects from exposure to the four potential hazardous exposures related to the 1991 Gulf War. These included sarin, depleted uranium, vaccinations, and pyridostigmine bromide ("PB," a nerve agent protecting drug used by DoD). The report contained 13 findings, of which four indicated a positive association between some health outcome and the reviewed general risk factors. Many were obvious, such as an association between a large exposure to the military nerve agent sarin and severe health effects including death. Others were related to common side effects of drugs and vaccines seen among civilians or military personnel using these agents to protect their health.

Following review by a VA Task Force, VA determined that establishing new presumptions of service connection for any diseases based on the report findings was not necessary. This was primarily because the types and degree of exposures associated with long-term health effects described in the NAS Committee report had either not occurred during the 1991 Gulf War (for example, severe, life-threatening and immediate nerve agent poisoning), or that the related health effects were transitory and short-lived (for example, a normal sore arm following a vaccination). Those findings were published in the Federal Register, as required by the relevant statutes that established this process.

The 2002 NAS Report. The second 2002 NAS Committee report, "Gulf War & Health Volume 2," reviewed health effects from exposure to pesticides and solvents used during the 1991 Gulf War. An important issue was that virtually all the pesticides and solvents used during that conflict were in common approved use throughout the civilian and military at that time. The report contained 77 findings, of which 21 indicated a positive association between a pesticide or a solvent and some general health outcome. These were primarily for various cancers and serious hematological disorders (e.g., leukemias, non-Hodgkin's lymphoma, multiple myeloma and aplastic anemia), subtle general neurological effects detected via neurobehavioral tests, and other health effects (e.g., reactive airway dysfunction syndrome, and allergic contact dermatitis).

Following review by a VA Task Force, VA determined that it was not necessary to establish new presumptions of service connection for any diseases based on the report findings. This was in part because the NAS Committee findings were generally limited to long-term, chronic occupational exposures that do not directly correlate to potential hazards of service or exposure scenarios for the 1991 Gulf War. Furthermore, individuals who were chronically exposed to relatively high levels of these environmental hazards as part of their military occupation, whether or not during service in that war, may qualify under existing VA service connection policies for benefits for diseases resulting from such exposures. It should be pointed out that VA's decision to not establish any new presumptions does not alter existing claim procedures, nor does it prevent any veteran from establishing service connection for any disease that could be related to their service in the 1991 Gulf War. Rather, it merely means that each case must be decided on its facts and merits, as is currently the case for veterans from any era.

The 2004 NAS Sarin Update Report. In 2004, at the request of the Secretary of Veterans Affairs, a new NAS Committee completed a special update on long-term health effects from exposure to the nerve agent sarin. The initial 2000 NAS Committee report described above had concluded that available scientific evidence could not show an association between trace sarin exposure and subsequent long-term adverse health effects. In response, the Secretary of Veterans Affairs determined that there was not an adequate basis to support establishing presumptive service connection for any long-term health problems resulting from low-level sarin exposure.

After the completion of the 2000 NAS Committee report, several new studies on sarin effects in laboratory animals were published that were not available to the NAS Committee when they conducted their initial review, and which some saw as requiring a new look by the NAS committee. The new NAS Committee reviewed 19 epidemiological studies of sarin health effects published since the earlier 2000 report, including studies of U.S. and U.K. veterans of the 1991 Gulf War potentially exposed at Khamisiyah, Iraq in 1991, of civilians exposed during the Japan sarin terrorist attacks in 1994 and 1995, and all the studies used in the earlier 2000 NAS Committee report. They also reviewed over 100 animal studies.

The August 2004 NAS Sarin Update came to the same conclusions as the earlier 2000 report. In other words, and consistent with their earlier findings, the NAS Committee was not able to find a scientific basis to associate any disease with exposure to low levels of sarin, based upon their exhaustive review of the relevant scientific literature.

The 2004 NAS Report. The third full NAS Committee report, "Gulf War & Health Volume 3: Fuels, Combustion Products, and Propellants," contained nine positive findings on long-term health effects related to exposure to the reviewed agents. These included associations between exposure to combustion products (e.g., smog) and lung cancer, cancers of nasal cavity and nasopharynx, cancers of the oral cavity and oropharynx, laryngeal cancer, bladder cancer, low birth weight/intrauterine growth retardation and exposure during pregnancy, preterm birth and exposure during pregnancy, and incident asthma. They also reported an association between exposure to hydrazine rocket fuels and lung cancer. As with previous reports, an important point is that most of the agents considered were in common use throughout the civilian and military at the time of the 1991 Gulf War.

The NAS Committee considered over 33,000 potentially relevant references, and focused on about 800 epidemiological studies on persistent health outcomes associated with exposure to oil-fire products, diesel-heater fumes, hydrogen sulfide (a specific combustion product), hydrazines and red fuming nitric acid (as rocket propellants), and gasoline and jet fuel. The Committee pointed out that fuels and related combustion products are common pollutants with an abundant scientific health literature available for their review. Combustion products included ambient air pollution "smog," combustion products from motor vehicles, and fumes from stoves and heaters using a wide variety of fuels. Fuels included gasoline, kerosene, diesel and military fuels including JP–4, JP–5 and JP–8. Finally, to ensure a focus on information that would be the most relevant to veterans of the 1991 Gulf War, the Committee emphasized studies of long-term rather than short-term health effects. A VA Task Force reviewing the new NAS Committee report determined that new presumptive service connections were not warranted because none of the specific hazardous agents reviewed, or the exposure levels experienced by most Gulf War service members, were significantly different compared to U.S. civilians or to troops not deployed to the Gulf War.

The 2006 NAS Report "Volume 4: Health Effects of Serving in the Gulf War:" The September 2006 fourth full NAS report reviewed peer-reviewed scientific literature on the health status of veterans of the 1991 Gulf War. The report was intended to inform VA about illnesses and clinical issues including possible relevant treatments, which might have been overlooked among this population, regardless of the specific underlying cause. It documented increased rates of certain illnesses among Gulf War veterans, based on a review of 850 epidemiological and other studies of this group, which they selected from among over 4,000 potentially relevant reports. They concluded that "VA and DoD have expended enormous effort and resources in attempts to address the numerous health issues related to the Gulf War veterans. The information obtained from those efforts, however, has not been sufficient to determine conclusively the origins, extent, and potential long-term implications of health problems potentially associated with veterans' participation in the Gulf War."

The NAS Committee identified numerous serious limitations in existing epidemiological studies of Gulf War veterans, in large part due to the lack of veteran exposure data. However, they did "not recommend that more such studies be undertaken for the Gulf War veterans." Rather, the Committee recommended "continued sur-

veillance to determine whether there is actually a higher risk in Gulf War veterans" for illnesses that current research has identified as possibly appearing at higher rates among Gulf War veterans, specifically, brain and testicular cancer, ALS, birth defects, and post-deployment psychiatric conditions.

The NAS Committee also concluded, "Every study reviewed by this Committee found that veterans of the Gulf War report higher rates of nearly all symptoms examined than their nondeployed counterparts." Not surprisingly, they reported that symptom-defined "unexplained illnesses," consistent with Chronic Fatigue Syndrome, Fibromyalgia, Irritable Bowel Syndrome and Multiple Chemical Sensitivity, were the most common health problem reported in studies of Gulf War veterans. However, they concluded that "the results of that research indicate that although deployed veterans report more symptoms and more severe symptoms than their nondeployed counterparts, there is not a unique symptom complex (or syndrome) in deployed Gulf War veterans."

They also found that "Gulf War veterans consistently have been found to suffer from a variety of psychiatric conditions," including PTSD, anxiety, depression and substance abuse. Similarly, they found that available studies have "not demonstrated differences in cognitive and motor measures" in deployed versus non-deployed veterans, and show no apparent increase in risk of peripheral neuropathy, cardiovascular disease or diabetes. Finally, they reported difficulties in interpreting data on birth defects, and found little data supporting objective respiratory illnesses among Gulf War veterans. A VA Task Force reviewing the new NAS Committee report determined that new presumptive service connections were not warranted because existing VA policies and procedures for disability compensation effectively cover veterans with these health problems. These include, for example, VA policies recognizing service connection for PTSD, and for service connection for difficult to diagnose or undiagnosed illnesses.

The 2006 Report "Infectious Diseases." The October 2006 fifth NAS report in this series, "Gulf War and Health Vol. 5: Infectious Diseases," reviewed published, peer-reviewed scientific and medical literature on long-term health effects from infectious diseases associated with Southwest Asia, including those diseases relevant to the 1991 Gulf War and to Operations Iraqi Freedom and Enduring Freedom (OIF/OEF). They identified over 20,000 potentially relevant scientific reports, and focused on 1,200 that had the necessary scientific quality.

They focused on nine infectious diseases that were 1) prevalent in Southwest Asia, 2) diagnosed among U.S. or other troops serving there, and 3) known to cause long-term health problems. They also focused upon those infectious diseases that appeared to be of special concern to veterans who served in Southwest Asia. These were Brucella (causing brucellosis); Campylobacter; Salmonella and Shigella (causing diarrheal disease); Coxiella burnetii (causing Q fever); Leishmania (causing leishmaniasis); Mycobacterium tuberculosis (causing tuberculosis); Plasmodia (spp) (causing malaria) and West Nile Virus (causing West Nile fever). They selected these from among about 100 naturally occurring pathogens that potentially could have infected U.S. troops in the 1991 Gulf War, or in OIF/OEF. The NAS Committee identified 34 different long-term health effects in their report that might appear weeks to years after initial infection, associated with these nine infectious diseases. Most if not all identified long-term health effects are well-known to be associated with the initial acute infection. A VA Task Force is currently reviewing the new NAS Committee report to determine if new presumptive service connections are warranted.

OTHER REVIEWS ON GULF WAR VETERANS' HEALTH

The IOM's reputation for scientific rigor, independence from the political process, and freedom from bias has made it an influential source of information on the nature of Gulf War veterans' health. In addition, since the end of the 1991 Gulf War, at least 13 other committees have been established, both in the United States and the United Kingdom, to help evaluate Gulf War veteran health issues. Other Committees (and date of publications) include:

- Armed Forces Epidemiological Board (AFEB). U.S. Department of Defense, 1996, 1999, 2000, 2000.
- Goss Gilroy Inc. Canadian Epidemiological Study of Gulf War Veterans. 1998.
- The Rt Hon The Lord Lloyd of Berwick. Independent Public Inquiry on Gulf War Illnesses. 2004.
- U. S. Department of Veterans Affairs, Research Advisory Committee on Gulf War Veterans Illnesses, James Binns, Chair. Scientific Progress in Understanding Gulf War Veterans' Illnesses: Report and Recommendations, 2004.

- U.S. Department of Defense Special Oversight Board for Department of Defense Investigations of Gulf War Chemical and Biological Incidents. Final Report, 2000.
- U.S. Department of Defense. Report of the Defense Science Board Task Force on Persian Gulf War Health Effects, 1994.
- U.S. Department of Health & Human Services, National Institutes of Health Technology Assessment Workshop Panel. The Persian Gulf Experience and Health. 1994 U.S. government Accountability Office (GAO). Gulf War Illnesses: DoD's Conclusions About U.S. Troops' Exposure Cannot Be Adequately Supported. 2004
- U.S. Presidential Advisory Committee on Gulf War Veterans' Illnesses: Interim Report. 1996
- U.S. Presidential Advisory Committee on Gulf War Veterans' Illnesses: Final Report. 1996.
- U.S. Presidential Advisory Committee on Gulf War Veterans' Illnesses: Special Report, 1997.
- United Kingdom Parliamentary Office of Science and Technology. Gulf War illnesses: Dealing with the Uncertainties. 1997.
- U.S. Senate, Committee on Veterans' Affairs, Report of the Special Investigation Unit on Gulf War illnesses. 1998.

Collaboration with the VA Gulf War Veterans Research Advisory Committee. One of the most recent advisory groups on Gulf War veteran health issues has been the VA Research Advisory Committee (RAC) on Gulf War Veterans Illnesses, chaired by Mr. James Binns. VA has been pleased with recent efforts with the RAC to lay the groundwork for improved research on Gulf War veterans' health. VA and the RAC have agreed to several important steps to improve the quality of VA's Gulf War research portfolio. The RAC has recommended scientific experts to serve as research review panel members of a new scientific merit review board. In addition, VA consults with the RAC regarding the relevancy of proposals that have been identified as being fundable. VA and the RAC will also work together to identify researchers who can partner with VA investigators.

VA RESEARCH ON GULF WAR VETERANS' HEALTH

VA's Office of Research and Development (ORD) early on recognized that while there were few visible casualties associated with the 1991 Gulf War, many individuals returned from this conflict with unexplained medical symptoms and illnesses. To date, VA, DoD and the Department of Health and Human Services (HHS) have funded a total of 330 projects pertaining to the health consequences of military service in the Gulf War, as described in Annual Reports to Congress on federally Sponsored Research on Gulf War Veterans' Illnesses. Although the causes and successful treatment of GWVI remain illusive VA's ORD has committed to continued funding of relevant research in this area.

In addition, the Institute of Medicine recently announced (in a report described in more detail later) that Gulf War and other combat veterans may be at increased risk for amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease) as a result of their service. Accordingly, VA's ORD is supporting a research portfolio composed of studies dedicated to understanding chronic multi-symptom illnesses, long-term health effects of potentially hazardous substances to which Gulf War veterans may have been exposed to during deployment and conditions and/or symptoms that may be occurring with higher prevalence in Gulf War veterans, such as ALS, multiple sclerosis and brain cancer.

While VA, DoD and HHS funds its Gulf War research independently, each closely coordinates its efforts with the others to avoid duplication of effort and to foster the highest standards of competition and scientific merit review for all research on illnesses in Gulf War veterans. The Research Subcommittee of the Deployment Health Work Group, which is a component of the VA/DoD Health Executive Council, currently conducts this coordination. HHS participates in both the Deployment Health Work Group and its Research Subcommittee.

ALS RISK AMONG VETERANS

ALS is a rare, progressive and nearly always fatal disease of the nervous system. About 5 to 10 percent of cases appear to be inherited but the cause of the remaining 90 to 95 percent of cases is not known. Although certain environmental exposures have been considered as potential causes of ALS, none have been clearly tied to this disease.

In December 2001, based on pre-publication announcements from two studies suggesting that Gulf War veterans were at greater risk for ALS, VA announced that it would explore options for compensating veterans who served in the Gulf War and

who subsequently develop amyotrophic lateral sclerosis (ALS). VA in 2001 implemented a policy of referring all Gulf War ALS claims to VA's Central Office for special review.

More recent scientific publications suggest that all veterans may be at greater risk of developing ALS. A 2005 study published in the journal Neurology (Weisskopf et al.) evaluated ALS risk among veterans from World War 2, and the Korean and Vietnam Wars, and reported as a group these veterans were at significantly greater risk for ALS compared to civilians. The two studies that supported VA's ALS policy for Gulf War veterans were published in 2003, and also suggested that veterans from the 1991 Gulf War were at similarly greater risk for ALS (Horner et al., Haley).

In response to the suggestion that all veterans might be at an increased risk of ALS, in May 2005, VA contracted with the NAS/IOM to evaluate the scientific basis of all relevant studies. In their November 10, 2006, report the IOM Committee concluded that although there are significant limitations to these studies, there is "limited and suggestive evidence of an association between military service and later development of ALS."

What the IOM Found. Following a thorough review of relevant scientific literature, the IOM Committee in their November 2006, report identified one "high-quality cohort study that adequately controlled for confounding factors and reported a relationship between serving in the military and later developments of ALS" (the Weisskopf study). They also found "three related studies [that] supported the association" but which were of variable quality (which included the Gulf War veteran studies).

They concluded, "On the basis of its evaluation of the literature, the Committee concludes that there is limited and suggestive evidence of an association between military service and later development of ALS." This is the IOM's weakest positive category of association for a health effect. However, the Committee concluded, "[a]lthough the study has some limitations... overall it was a well-designed and well conducted study. It adequately controlled for confounding factors (age, cigarette use, alcohol consumption, education, self-reported exposure to pesticides and herbicides, and several main lifetime occupations)."

A VA Task Force consisting of the Under Secretaries for Health and for Benefits, the OGC, and the DAS for Policy and Planning was established to review the new IOM report.

VA Research on ALS. Although presently, there is no effective treatment for ALS, ORD currently supports a broad research portfolio dedicated to understanding the cause(s) and treatment for this devastating disease. Recent advances in neurological research may allow for the development of strategies to promote the restoration of nerve function. The development of novel strategies and technologies for the development and delivery of therapeutics for ALS patients remains an important goal in ALS research. ORD-funded projects are directed toward improving our understanding of the continuum of the development, progression, treatment and prevention of ALS."

Several VA investigators are conducting research on ALS as it relates to military service during the first Gulf War. This work includes identification of biological markers to identify cases of ALS, examination of the effects of pesticides and insecticides used during the Gulf War on the progression of ALS and examination of the prevalence of ALS in Gulf War veterans. One project is examining the overall and cause-specific mortality risk of ALS, multiple sclerosis (MS) or brain cancer in a group of more than 620,000 Gulf War veterans and assessing the demographic, military and in-theater exposure characteristics associated with the risk of deaths from these diseases.

VA researchers are also studying new ways to selectively increase the ability of therapeutic agents to enter the brain and spinal cord without compromising the blood brain barrier. While this barrier protects the central nervous system from harmful agents, it also limits the ability of many therapeutic agents to enter the brain.

VA investigators have ongoing research projects studying the use of stem cell transplants as a means to restore lost function following the loss of neurons associated with ALS, Alzheimer's disease, Parkinson's disease, spinal cord injury and stroke. Stem cells derived from neurons, as well as from hematopoietic (blood) cells, are being studied. It is hoped that these stem cells will mature into adult neurons and replace damaged neurons. In addition, VA investigators are examining gene therapy to deliver growth factors and other small molecules needed for regeneration and/or protection of the brain and spinal cord.

VA investigators are also examining the use of a neuromotor prosthesis to enhance communication and increase independence for veterans suffering from ALS.

A neuromotor prosthesis is a brain-computer interface that uses an electrode that picks up brain signals and sends them to a computer for decoding. The brain signals are translated into commands to power electronic or robotic devices, or to communicate via word processing, e-mail or the Internet. VA researchers have already demonstrated the potential usefulness of this technology in an ALS patient and are developing multi-site studies designed to improve this technology and improve the lives of individuals suffering from this disease and their families.

ORD also supports a national registry of veterans with ALS to identify, as completely as possible, all veterans with ALS and to collect data for studies examining the causes of ALS. The registry is designed to track the health status, collect DNA samples and clinical information and provide a mechanism for VA to inform veterans with ALS about research studies for which they may be eligible to participate. The registry will provide VA with a valuable mechanism for involving veterans in clinical trials and other studies that may yield improved outcomes for ALS. In addition, data gathered as part of the registry has the potential to benefit not only veterans, but also the larger community of individuals with ALS.

Other exciting ALS projects supported by ORD include a 15-site clinical trial to determine the tolerability and efficacy of sodium phenylbutyrate (NaPB) as a new therapy for ALS, and a study examining a compound that has been shown to delay the onset of ALS symptoms in animal models of the disease. Finally, ORD supports a cooperative effort to collect and store high-quality biological specimens donated by veterans diagnosed with ALS for use in biomedical research.

Anthrax Vaccine Research. ORD supports a study utilizing state of the art technology to investigate and characterize the response of human cells to anthrax vaccination and other agents. This study represents a novel approach to identifying underlying mechanisms operating in specific cell populations which are influenced in response to exposure to anthrax vaccination. It is hoped that this study will disclose biological processes that may improve our understanding of the illnesses affecting Gulf War veterans.

LESSONS LEARNED

VA developed a wide range of health care and research programs to benefit veterans of the 1991 Gulf War. Lessons learned from this process have provided significant benefits to new combat veterans returning today from Southwest Asia. Both groups of combat veterans—those who served in the 1991 Gulf War and those who are serving in OEF and OIF, remain a high priority for VA. This issue of a possible increased risk for being diagnosed with ALS for all service members remains a large concern for VA. In response, VA has initiated new research on this possibility, and is considering how to respond to findings of the recent IOM report on this issue.

Attachment: 19 Studies on Gulf War Veterans' Health Issues by the National Academy of Sciences Institute of Medicine (IOM) (available on line at www.nap.edu).

Congressionally Mandated "Gulf War & Health" Studies (by Public Laws 105–277 and 105–368)	
"Gulf War and Health: Volume 1. Depleted Uranium, Pyridostigmine Bromide, Sarin, and Vaccines." 2000	"Gulf War and Health: Volume 3. Fuels, Combustion Products, and Propellants." 2005
"Gulf War and Health: Volume 2. Insecticides and Solvents." 2003	"Gulf War and HealthVol. 4: Health Effects of Serving in the Gulf War." 2006
"Gulf War and Health: Updated Literature Review of Sarin." 2004	"Gulf War and Health Vol. 5: Infectious Diseases." 2006

Other Gulf War Veteran's Health Studies—Clinical and Policy Evaluations—continued	
"Gulf War Veterans: Treating Symptoms and Syndromes." 2001	"An Assessment of the Safety of the Anthrax Vaccine: A Letter Report." 2000
"Protecting Those Who Serve: Strategies to Protect the Health of Deployed U.S. Forces." 2000	"Strategies to Protect the Health of Deployed U.S. Forces: Detecting, Characterizing, and Documenting Exposures." 2000
"Measuring the Health of Persian Gulf Veterans: Workshop Summary." 1998	"Gulf War Veterans: Measuring Health." 1999
"Strategies to Protect the Health of Deployed U.S. Forces: Medical Surveillance, Record Keeping, and Risk Reduction." 1999	"National Center for Military Deployment Health Research." 1999
"Adequacy of the VA Persian Gulf Registry and Uniform Case Assessment Protocol." 1998	"Adequacy of the Comprehensive Clinical Evaluation Program: A Focused Assessment." 1997
"Adequacy of the Comprehensive Clinical Evaluation Program: Nerve Agents." 1997	"Health Consequences of Service During the Persian Gulf War: Recommendations for Research and Information Systems." 1996
"Health Consequences of Service During the Persian Gulf War: Initial Findings and Recommendations for Immediate Action." 1995	

Statement of Shannon L. Middleton, Deputy Director, Veterans Affairs and Rehabilitation Commission, American Legion

Mr. Chairman and Members of the Subcommittee:

The American Legion appreciates the opportunity to offer our views on this very important issue. American military forces are currently engaged in combat operations in Iraq and Afghanistan and it is easy to forget that there are still thousands of veterans from the 1991 Gulf War still suffering from unexplained multi-symptom illnesses related to their service in Southwest Asia. We applaud this Subcommittee for not forgetting these veterans and holding this hearing.

History of Undiagnosed Illness Compensation

Shortly after the end of the 1991 Gulf War, thousands of Gulf War veterans began complaining of unexplained multi-symptom illnesses (headaches, fatigue, muscle pain, joint pain, gastrointestinal problems, neurological signs and symptoms, etc.). In most cases, doctors were not able to provide definitive diagnoses. As a result, compensation claims filed with the Department of Veterans Affairs (VA) were being denied outright since VA was prohibited by law from "service-connecting" conditions that could not be diagnosed. As result of strong lobbying efforts by the veteran service organization community and others to correct this problem, Public Law 103–446 (38 USC § 1117) was enacted in 1994, authorizing VA to pay compensation to disabled Gulf War veterans suffering from undiagnosed illnesses. The undiagnosed illness must have become manifest either while the veteran was in the Southwest Asia theater of operations or prior to January 1, 2012, if symptoms first developed after the veteran left Southwest Asia. Although PL 103–446 was clearly intended to compensate ill Gulf War veterans suffering from undiagnosed or medically unexplained conditions, vague wording in the final version of the law allowed VA to publish restrictive implementing regulations, resulting in a very high denial rate under

the new law. Conditions such as fibromyalgia, irritable bowel syndrome, and chronic fatigue syndrome, although medically unexplained, were considered to be "diagnosed" conditions and were being denied under the new undiagnosed illness law.

The VSO community again turned to Congress for help. The result was Public Law 107–103, signed into law on December 27, 2001. Effective March 1, 2002, provisions of this law clarified and further expanded the definition of undiagnosed illness under the law to include medically unexplained chronic multi-symptom illness, such as chronic fatigue syndrome, fibromyalgia, and irritable bowel syndrome, that is defined by a cluster of signs or symptoms. Signs or symptoms that may be a manifestation of an undiagnosed or chronic multi-symptom illness include the following: fatigue, unexplained rashes or other dermatological signs or symptoms, muscle pain, joint pain, neurological signs or symptoms, signs or symptoms involving the upper or lower respiratory system, sleep disturbances, gastrointestinal signs or symptoms, cardiovascular signs or symptoms, abnormal weight loss, or menstrual disorders. A disability is considered chronic if it has existed for at least 6 months.

Despite the enactment of PL 107–103, clarifying and expanding the definition of undiagnosed illness, the denial rate for these claims remains very high (approximately 75 percent). The restrictive nature of VA's final rule, published in the Federal Register on June 10, 2003, implementing the Gulf War provisions of PL 107–103 has reinforced this pattern. As of May 2007, less than four thousand such claims, out of almost 15,000 that have been processed, have been granted service connection.

The American Legion urges the House Veterans' Affairs Committee to conduct oversight of the Gulf War-related provisions of PL 107–103.

Compensation for Amyotrophic Lateral Sclerosis (ALS)

Preliminary findings of a joint Department of Veterans Affairs (VA) and Department of Defense (DoD) study, released in December 2001, of nearly 2.5 million veterans indicated that deployed Gulf War veterans (August 2, 1990 to July 31, 1991) are twice as likely as their non-deployed counterparts to develop ALS. The Secretary of Veterans Affairs immediately announced that he would explore VA's options for compensating Gulf War veterans who have been diagnosed with ALS. VA subsequently directed all VA regional offices to submit all Gulf War ALS cases to VA Central Office for expeditious adjudication. VA service-connected all Gulf War veterans (with service in Southwest Asia during the period of August 2, 1990 to July 31, 1991) identified with ALS at that time (approximately 40) on a direct basis, using the preliminary research findings as evidence to link ALS to the veterans Gulf War service.

Despite the Secretary's announcement and subsequent action, VA did not have plans to draft a regulation establishing an ALS presumption under current law guaranteeing compensation for Gulf War veterans who develop ALS in the future. The joint VA and DoD study was published in the scientific journal "Neurology" in September 2003, resulting in the Secretary publicly announcing that this "final study" supports his 2001 decision to compensate Gulf War veterans stricken with ALS. Despite this public announcement and the Secretary's initial decision to expeditiously service-connect, on a direct basis, Gulf War veterans diagnosed with ALS, VA informed The American Legion that it would be "premature" to create a regulatory presumption of service connection for Gulf War veterans with ALS. Bottom-line, although VA expeditiously service-connected a small number of veterans diagnosed with ALS, it has not established ALS as an official Gulf War presumptive disability and it has no plans to do so at this time based on its responses to specific American Legion inquiries. Without an actual presumption in place, there is nothing to ensure that Gulf War veterans diagnosed with ALS in the future will receive the same treatment as those discussed above. Due to the media coverage of VA's actions to expeditiously service-connect Gulf War veterans with ALS in December 2001, many people are under the erroneous belief that ALS is a Gulf War presumptive disability.

Additional studies have shown that military veterans in general have a greater likelihood than non-veterans of developing ALS. A study published in 2005 in the journal "Neurology" titled "Prospective study of military service and mortality from ALS," [M.G. Weisskopf et al., 2005; 64:32–37] evaluated ALS risk for veterans from World War 2, and the Korean and Vietnam Wars. This study concluded that these veterans were at significantly higher risk for ALS compared to civilians. In November 2006, the Institute of Medicine (IOM) released a report concluding "there is limited and suggestive evidence of an association between military service and later development of ALS." We understand that VA has finished its evaluation of the November 2006 IOM report in order to determine if any changes in VA health care or disability compensation policies are warranted but has determined that more re-

search is needed and a presumption is not warranted at this time. Although IOM also noted that additional research is needed regarding a link between military service and ALS, we submit that IOM's finding of "limited and suggestive" evidence between ALS and military service is sufficient, under current law, for VA to move forward and establish official ALS service connection presumptions. Even though veterans can, in theory, establish service connection without a specific military presumption, it is extremely difficult in most cases for the veteran to meet the burden of proof required by VA for establishing direct service connection and many veterans will be precluded from establishing entitlement to service connection for ALS without an actual presumption.

Gulf War Presumptive Disabilities

Research is inextricably intertwined with an ill Gulf War veteran's ability to receive VA compensation for specific conditions he/she believes are related to his/her Gulf War service. 38 USC § 1118 (PL 105–277), allows the Secretary of Veterans Affairs to establish presumptions of service connection for specific diagnosed conditions/diseases when scientific research supports a positive association with a known Gulf War exposure (vaccines, nerve agents, depleted uranium (DU), oil well smoke, etc.). The Secretary relies primarily on the IOM literature reviews and subsequent reports (Gulf War and Health) to determine whether a positive association exists to justify the establishment of a presumption. IOM?s reports to date (Volume 1: Depleted Uranium, Pyridostigmine Bromide, Sarin, Vaccines; Volume 2: Insecticides and Solvents; Volume 3: Fuels, Combustion Products, and Propellants; Volume 4: Health Effects of Serving in the Gulf War;Volume 5: Infectious Disease), and an August 2004 updated literature review of sarin **have not** provided the scientific evidence necessary for VA to establish presumptive disabilities for any of the exposures looked at by IOM so far. As a result, not one presumptive disability has been established to date under this law.

Congress directed IOM's reports to be based on findings from the full range of human and animal studies that provide information on the effects of Gulf War-related exposures, as well as both diagnosed and undiagnosed illnesses affecting Gulf War veterans. IOM's "Gulf War and Health" series of reports, as commissioned by VA, have not adhered to requirements set forth by Congress in mandating the reports. As a result, they have not comprehensively addressed key questions regarding Gulf War-related health conditions in relation to Gulf War exposures. IOM's reports to date have not considered findings from epidemiologic studies of Gulf War veterans (i.e. association of Gulf War veterans' illnesses with exposures), nor have they considered animal studies in drawing its conclusions. A perfect example of this is the August 2004 updated literature review of sarin. The Secretary of VA commissioned this review because studies published subsequent to IOM's September 2000 report (Volume 1), that addressed sarin, showed that exposure to sarin even at levels too low to cause immediate/acute effects can still have long-term adverse health effects (brain damage). Even though these studies were the reason the Secretary wanted IOM to look at sarin again, IOM did not even consider this research when drawing its conclusions because they were animal-based studies.

Research

In the Research Advisory Committee on Gulf War Veterans' Illness (RACGWI) initial report released in November 2004, it was found that, for a large majority of ill Gulf War veterans, their illnesses could not be explained by stress or psychiatric illness and concluded that current scientific evidence supports a probable link between neurotoxin exposure and subsequent development of Gulf War veterans' illnesses. Earlier government panels concluded that deployment-related stress, not the numerous environmental and other exposures troops were exposed to during the war, was likely responsible for the numerous unexplained symptoms reported by thousands of Gulf War veterans.

Gulf War research is moving away from the previous stress theories and is actually starting to narrow down possible causes. However, research regarding viable treatment options is still lacking. The American Legion applauds Congress for having the foresight to provide funding to the Southwestern Medical Center's Gulf War Illness research program. The Center, headed by Dr. Robert Haley at the University of Texas Southwestern, was awarded $15 million, renewable for 5 years, to further the scientific knowledge on Gulf War Veterans Illnesses research. This research will not only impact veterans of the 1991 Gulf War, but may prove beneficial for those currently serving in the Southwest Asia Theater and the Middle East during the Global War on Terror. The purpose of the research is to fill in the gaps of knowledge where there is little, yet suggestive, information. Dr. Haley's research will further this knowledge about Gulf War veterans' illnesses and hopefully help improve the

lives of ill Gulf War veterans, and their families who suffer beside them. We owe ill Gulf War veterans our exhaustive efforts in finding treatments for their ailments. The American Legion believes that VA should continue to fund research projects consistent with the recommendations of the Research Advisory Committee on Gulf War Veterans' Illness (RACGWI). It is important that VA continues to focus its research on finding medical treatments that will alleviate veterans' suffering as well as on figuring out the causes of that suffering. The American Legion also recommends that the Subcommittee thoroughly review the RACGWI's second report, which will be released this fall.

Health Care

Public Law 103–210, which authorized the Secretary of Veterans Affairs to provide priority health care to the veterans of the Persian Gulf War who have been exposed to toxic substances and environmental hazards, allowed Gulf War Veterans to enroll into Priority Group 6. The last sunset date for this authority was December 31, 2002. Since this date, information provided to veterans and VA hospitals has been conflicting. Some hospitals continue to honor Priority Group 6 enrollment for ill Gulf War veterans seeking care for their ailments. Other hospitals, well aware of the sunset date, deny Priority Group 6 enrollment for these veterans and notify them that they qualify for Priority Group 8. To the veterans' dismay, they are completely denied enrollment because the VA has restricted enrollment for Priority Group 8 since January of 2003. Even more confounding is the fact that eligibility information disseminated via Internet and printed materials does not consistently reflect this change in enrollment eligibility for Priority Group 6. The American Legion has been assured by VA that this issue will be rectified.

The American Legion believes priority health care should be again extended to Gulf War veterans seeking treatment for ailments related to environmental exposures in theater. Although these veterans can file claims for these ailments and possibly gain access to the health care system once a disability percentage rate is granted, those whose claims are denied cannot enroll. According to the May 2007 version of VA's Gulf War Veterans Information System (GWVIS), there were 14,874 claims processed for undiagnosed illnesses. Of those undiagnosed illness claims processed, 11,136 claims were denied. Because the nature of these illnesses are difficult to understand and information about individual exposures may not be available, many ill veterans are not able to present strong claims. They are then forced to seek care from private physicians who may not have enough information about Gulf War veterans' illnesses to provide appropriate care.

Since VA doctors would be more knowledgeable about the exposures Gulf War veterans experienced in theater, it is important that VA keeps Gulf War Continuing Medical Education (CME) updated to reflect current science. It is equally important that, once updated, VA makes Gulf War CMEs a requirement, not an option, to better serve this population of ill veterans. Although reputable research Committees have shown that Gulf War veterans are sicker than those who did not deploy to the Southwest Asia theater, The American Legion is still contacted by veterans complaining that some VA doctors do not know how to treat their Gulf War illnesses. In fact, some ill Gulf War veterans are still being told that their illnesses are all in their heads.

Outreach

It is The American Legion's understanding that VA has stopped mailing out printed copies of the Gulf War Review and is now only posting it online. We are concerned, not only because not all Gulf War veterans have Internet access, but the VA's Gulf War veterans page is difficult to locate from VA's main web page. Only those who know where it is located, or that it even exists, will have access to the information. The American Legion has had several calls from those who inquired about the printed newsletter, as well as those who were interested but had no Internet access. We urge VA to resume mailing out printed versions of the Gulf War Review in addition to posting it on the web.

Again, thank you Mr. Chairman for giving The American Legion this opportunity to present its views on such an important issue. We look forward to working with the Subcommittee to address this and other issues affecting veterans.

Statement of Hon. Corrine Brown,
a Representative in Congress from the State of Florida

Thank you, Mr. Chairman for calling this hearing today.

Gulf War Illnesses have bedeviled the doctors of the Department of Defense and the Veterans Administration.

About 670,000 troops from the United States served in this conflict. They served from just after the invasion of Kuwait on August 2, 1990 until June 13, 1991.

While the troops have long been returned home from this conflict, their suffering continues, 16 years later. For years, the VA and DoD rejected the complaints of the veterans that they were sick and were told they were imagining things.

Well, they were not imagining things and the experience of war affects everyone differently. We are learning that from the current wars in Iraq and Afghanistan.

What have we learned from the Persian Gulf War?

Are we taking these lessons and protecting the soldiers in Iraq and Afghanistan?

I know the Department of Defense is collecting data from soldiers. Is it the right data?

Is the VA and DoD cooperating in the discussion of symptoms and illnesses soldiers are coming home with? Are they sharing the data.

Do we have numbers of veterans complaining of unknown illnesses? We have a pretty good idea of those suffering from TBI or PTSD. What about what we don't know?

I look forward to hearing the testimony today.

Statement of Dan Fahey, San Francisco, CA (Ph.D., Candidate, University of California-Berkley)

Dear Chairman Filner and Honorable Members of the House Veterans Affairs Committee:

I respectfully submit to you this written testimony on the occasion of your hearing on Gulf War veterans' illnesses to call your attention to serious problems with the Department of Veterans Affairs (DVA) study of Gulf War veterans exposed to depleted uranium (DU). Since 1993, I have interviewed hundreds of veterans about battlefield exposures to dust and debris from armor-piercing DU ammunition and presented my research findings to numerous Federal investigations of Gulf War veterans' illnesses. I am including with this testimony a copy of my most recent presentation at the 28 June 2007 meeting of the Institute of Medicine (IOM) Committee that is reviewing scientific and medical literature on the health effects of DU exposure. My IOM presentation provides more detailed information in support of this statement.

The Department of Veterans Affairs study of DU is neither structured nor functioning to provide basic information about the possible health effects of DU exposure among Gulf War veterans. There are two major flaws with the study that undermine its integrity and value. First, the DVA study is undersized. From its inception in 1993, the study included only a tiny fraction of the number of veterans with known or suspected exposures to DU. Consequently, we have no information about the possible health effects among the thousands of Gulf War veterans exposed to DU in friendly fire incidents; during the recovery, transport, and inspection of contaminated equipment; and as a result of the July 1991 munitions fire at Doha, Kuwait.

Second, the DVA study has become politicized. In recent years, officials from both the Department of Defense (DoD) and DVA have repeatedly presented false and incomplete information about the existence of cancers and tumors among the few dozen veterans being studied. The deceitful statements and omissions by DoD and DVA officials undermine the integrity of the study and call to question its purpose.

The DVA study of veterans exposed to DU is located at the Baltimore VA Medical Center and directed by Dr. Melissa McDiarmid. When DVA created the study in 1993, only 33 Gulf War veterans were enrolled. These individuals had been heavily exposed to DU as a result of being inside vehicles hit by DU rounds in friendly fire incidents; some had been wounded by DU fragments while others inhaled DU dust. A 1993 DVA report on the creation of the study noted: "The small size of the population—[makes it] highly unlikely that definitive conclusions concerning cancer induction will be obtained from the study." By 2000, however, DoD belatedly admitted that "thousands" of Gulf War veterans may have been exposed to DU during and after the Gulf War, including approximately 900 veterans who are believed to have

had heavy exposures to DU during friendly fire incidents, vehicle recovery operations, and the Doha, Kuwait munitions fire. Despite this admission, since 2001 the DVA study has examined only 46 individual Gulf War veterans. Since numerous laboratory studies have demonstrated that DU may cause cancers, tumors, neurological problems, and other effects, it is imperative to expand and improve the DVA study in order to clarify the association between exposure to DU and cancer induction or other illnesses among Gulf War veterans.

In addition to studying only a few dozen veterans, the DVA study director has not honestly and completely presented study findings either publicly or in the medical literature. This fact first emerged in 2001, when DoD and DVA officials responded to European concerns that the use of DU munitions by U.S. jets during the Kosovo conflict had affected the health of NATO troops and civilians. At the height of the European controversy in January 2001, DVA study director Dr. Melissa McDiarmid wrote in the *British Medical Journal* that no veterans in her study had developed "leukemia, bone cancer or lung cancer," yet she inexplicably failed to mention that in 1999 one veteran in the study had Hodgkin's lymphoma and a second veteran had a bone tumor. Moreover, a 2006 journal article co-authored by Dr. McDiarmid supposedly summarized all study findings for the period 1993 to 2005, yet this article notably failed to mention the findings of the Hodgkin's lymphoma and bone tumor among the few dozen study participants. During her 28 June 2007 presentation to the IOM committee assessing the possible link between exposure to DU and health effects among veterans, Dr. McDiarmid again neglected to mention the findings of the Hodgkin's lymphoma and bone tumor.

These deceitful statements and omissions suggest that the DVA study is less a scientific study than a political tool used to downplay public concerns about DU and to mislead investigations of the connection between DU and health effects—such as the current IOM investigation—that could lead to an extension of service-connected benefits to Gulf War veterans for cancers or other illnesses.

I respectfully make the following recommendations to the House Veterans Affairs Committee:

- Initiate a U.S. Government Accountability Office investigation to clarify the purpose and findings of the DVA study, and to recommend how the study could be restructured to better serve the interests of both veterans and scientific inquiries into the health effects of exposure to depleted uranium; and
- Summon DVA study director Dr. Melissa McDiarmid to appear before the Committee to testify under oath about the number and type of cancers and tumors among study participants, and to explain why she has not honestly and thoroughly reported findings of cancers and tumors in the medical literature or to the IOM.

What is clearly needed at this point—16 years after Operation Desert Storm—is a study of *all* veterans with known or suspected DU exposures to determine rates of cancers, tumors, neurological problems, and other health effects potentially related to DU exposure; furthermore, there is an urgent need for a new study director who will accurately report study findings. I thank Chairman Filner for his sustained interest and action to investigate Gulf War veterans' illnesses and stand ready to assist the House Veterans Affairs Committee in its future work on this subject.

ADDENDUM TO

"DEPLETED URANIUM AND VETERANS HEALTH:

A FLAWED TESTING PROCESS AND AN UNDERSIZED, POLITICIZED STUDY LIMIT EVALUATION OF EXPOSURES AND EFFECTS"

Dan Fahey
Institute of Medicine
Washington, DC

28 June 2007

The following tables and narrative contain additional information about recommended limits on intake, exposure estimates, tumor formation, and Hodgkin's lymphoma. This information supplements my Power Point presentation to the Institute of Medicine, and is excerpted from:

Fahey, D. *In press*. "Depleted Uranium and Its Use in Munitions," and "Environmental and Health Consequences of Depleted Uranium Munitions," in Avril McDon-

ald (ed.) *The International Legal Regulation of the Use of Depleted Uranium Weapons: A Cautionary Approach*. Den Haag: Asser Press.

Table 1. Recommended limits on intake

	United States	Others
Members of the Public	0.05 mg/15 minutes [1] 0.5 mg/day [2]	0.035 mg/day [3] 4.5 mg/year [4]
Occupational Workers	0.18 mg/15 minutes [5] 2 mg/day [6] 10mg/week [7] 480mg/year [8]	0.18 mg/15 minutes [9] 2mg/day [10] 130mg/year [11]

Table compiled by Dan Fahey

The recommended limits on intake provide a basis from which to assess the significance of theoretical exposure estimates in a range of battlefield scenarios (Table 2). The Royal Society has generated a series of estimates intended to be generic for soldiers and civilians in conflicts where DU munitions are used.[12] In 1999, the U.S. Army Center for Health Promotion and Preventive Medicine developed a set of exposure estimates that were subsequently criticized as "incomplete and misleading" by the Presidential Special Oversight Board on Gulf War Veterans' Illnesses.[13] Consequently, the Army undertook a series of live-fire tests of DU rounds, known as the Capstone Project, and released revised estimates in 2004 (figures listed below are the Capstone estimates).[14] In 2005, Sandia national Laboratories (U.S.) published a study that included exposure estimates. The Royal Society, U.S. Army, and Sandia estimates are similar in some cases; in others they vary by orders of magnitude.

Table 2. Estimated intakes in exposure scenarios, durations of exposure

	Royal Society "Central" Estimate [15] (Time)	Royal Society "Worst-Case" Estimate [16] (Time)	U.S. Army "Most Likely" Estimate [17] (Time)	U.S. Army "Upper Bound" Estimate [18] (Time)	Sandia "Nominal Exposure" [19] (No duration specified)	Sandia "Maximum Exposure" [20] (No duration specified)
Soldiers in an armored vehicle penetrated by a DU round	250 mg (1 minute)	5000 mg (1 hour)	10–280 mg (1 minute) 43–710 mg (5 minutes)	91–970 mg (1 hour) 110–1000 mg (2 hours)	250 mg inhalation 330 mg fragments 15 mg ingestion	4000 mg inhalation 1800 mg fragments 500 mg ingestion
Soldiers who enter vehicles to rescue occupants immediately after a DU impact	250 mg (1 minute)	5000 mg (1 hour)	27–200 mg (10 minutes)	No estimate	250 mg inhalation 15 mg ingestion	4000 mg inhalation 500 mg ingestion
People who work in and around DU-impacted equipment	1 mg inhalation 0.5 mg ingestion (1 hour)	200 mg inhalation 50 mg ingestion (10 hours)	0.45 mg inhalation 10.6 mg Ingestion (1 hour)	14.5 mg inhalation 10.6 mg ingestion (1 hour)	40 mg inhalation 30 mg ingestion	600 mg inhalation 300 mg ingestion
Child at play	No estimate	No estimate	No estimate	No estimate	54 mg inhalation 3000 mg ingestion	226 mg inhalation 9000 mg ingestion
People downwind of DU-impacts	0.07 inhalation (passage of plume)	4.9 mg inhalation (passage of plume)	0.00006 mg inhalation (passage of plume)	0.04 mg inhalation (passage of plume)	0.003 mg inhalation	0.1 mg inhalation
Inhalation of resuspended DU from soil	0.8 mg [21] (27 days)	80 mg [22] (27 days)	No estimate	No estimate	0.001 mg inhalation	0.003 mg inhalation

Table compiled by Dan Fahey

5.1 **Cancer**

Laboratory studies have clearly demonstrated that DU is carcinogenic, but the link between DU and cancer in humans remains uncertain. Some of the uncertainties are related to the long latency period for development of cancers related to DU and the fact that few exposed humans have been studied. While the use of DU munitions appears unlikely to cause widespread cancers, sufficient evidence exists to support concerns that exposure to DU may lead to an elevated risk of cancer in heavily exposed populations.

5.1.1 *Laboratory studies*

*****

[TUMOR FORMATION]

Research conducted by the U.S. Armed Forces Radiobiology Research Institute (AFRRI) found that DU transformed human cells to a pre-cancerous phase; these cells then produced tumors when they were injected into mice.[23] The transformed cells also induced genetic instability and reduced production of a key tumor-suppressor protein.[24]

Other AFRRI studies found that DU causes DNA damage that might initiate and promote the formation of tumors.[25] The damage to DNA appears to be caused by both alpha radiation and chemical effects,[26] with delayed chromosomal damage observed in cells not directly irradiated by DU (the so-called "bystander effect").[27] "Considering that conventional understanding of potential DU health effects assumes that chemical effects are of greatest concern, results demonstrating that both radiation and chemical effects are involved in DU-induced cellular damage could have a significant impact on DU risk assessments."[28]

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5.1.3.1 *Hodgkin's Lymphoma*

The one cancer that has repeatedly shown up in surveys of veterans is Hodgkin's lymphoma (also known as Hodgkin's disease). Hodgkin's lymphoma develops in the lymph nodes, and it is a rare form of cancer (2.58 cases per 100,000 people in more developed countries; 0.94 cases per 100,000 in less developed countries[29]) with no known risk factor.[30] According to the Institute of Medicine:

"The lymphatic system is an important potential target for uranium radiation because inhaled insoluble uranium oxides can remain up to several years in the hilar lymph nodes of the lung. Studying the effect of uranium exposure on lymphatic cancer is more difficult than studying lung cancer because lymphatic cancer is much less common."[31]

In general, Hodgkin's lymphoma occurs more often among men and in people aged 15–34 and over 55.

In the United States, one out of 50 veterans examined in 1999 by the Department of Veterans Affairs" DU Program had Hodgkin's lymphoma.[32] It is worth noting that although this cancer was first reported in 1999 and discussed during an October 1999 meeting between the doctor in charge of the study and several Pentagon officials, in January 2001 a Pentagon official publicly denied the existence of this or any cancer among U.S. veterans in the DU study.[33]

In August 2002, the UK Ministry of Defence released a study showing that deaths due to lymphatic cancers were nearly twice as high among Gulf War veterans compared to a control group.[34] There is no publicly available information about the number of cases of Hodgkin's lymphoma versus the more-common Non-Hodgkin's lymphoma, but of the 3,172 Gulf veterans seen at the UK Gulf Veterans" Medical Assessment Programme as of 31 January 2003, 11 cases of lymphoma (including Hodgkin's and Non-Hodgkin's) had been reported.[35] The Ministry of Defence denies a link between these cancers and DU, but has initiated an additional study to clarify this finding.

Among Italian soldiers who served in Bosnia and/or Kosovo, "there is a disproportionately high number, which is statistically significant, of cases of Hodgkin's Lymphoma."[36] Although the Italian Defense Ministry could not identify the causes of this increase, it stated: "The results of sample studies carried out on Italian soldiers on duty in Bosnia and Kosovo have not shown evidence of depleted uranium contamination."[37] Overall, the Defense Ministry found a smaller-than-expected number of cancer cases among these soldiers.[38]

Endnotes

[1] This limit is for inhalation of insoluble uranium based on a short-term exposure limit of 0.15 mg/m^3 based on a breathing rate of 9.6 m^3 per 8-hour working day. U.S. National Institute for

Occupational Safety and Health (NIOSH), "Pocket Guide to Chemical Hazards," 1994; see also United Nations Environment Programme, "Depleted Uranium in Bosnia and Herzegovina." (Geneva: UNEP, 25 March 2003) p. 261.

[2] This limit is for inhalation of insoluble uranium based on chronic exposure limit of 0.05 mg/m^3 based on a breathing rate of 9.6 m^3 per 8-hour working day. NIOSH *supra* n. 107; see also United Nations Environment Programme, "Depleted Uranium in Bosnia and Herzegovina." (Geneva: UNEP, 25 March 2003) p. 261. Another reference states that the limit for inhalation of DU for members of the public equates to breathing a mass of 0.2 mg/day; R.L. Fliszar, "Radiological Contamination from Impacted Abrams Heavy Armor," Technical Report BRL–TR–3068 (Aberdeen Proving Ground, MD, Ballistic Research Laboratory December 1989) p. 18.

[3] The International Commission on Radiological Protection and the World Health Organization prescribe slightly different limits on intake by inhalation for members of the public, based partly on differences in limits based on chemical toxicity and radiation dose. To resolve this discrepancy, a recommendation has been made "that a unified . . . daily intake of 35 [micrograms] would be acceptable in most cases. This value would satisfy the constraints imposed by radiation dose and chemical toxicity. However, for protracted exposure to highly insoluble uranium compounds, a further threefold reduction may be considered appropriate." N. Stradling et al, "Anomalies between radiological and chemical limits for uranium after inhalation by workers and the public," 105 *Radiation Protection Dosimetry* (2003) 178.

[4] This refers to an inhalation of type S (insoluble) natural uranium and is based on a 1 micron activity mean aerodynamic diameter (AMAD). As noted above (see supra n. 8), the majority of DU particles created by an impact are insoluble. The limit for intake by inhalation of type M (moderately soluble) natural uranium is 13 mg/year; for type F (soluble) it is 75 mg/year. N. Stradling et al, "Anomalies between radiological and chemical limits for uranium after inhalation by workers and the public," 105 *Radiation Protection Dosimetry* (2003) p. 176. Another reference states "The Annual Limit of Intake for uranium-238, for a member of the public, as specified by the International Committee for Radiological Protection, equates to breathing in a mass of approximately 8 mg of Depleted Uranium." The Lord Gilbert, UK Ministry of Defense, letter to The Countess of Mar, 2 March 1998 (in author's files).

[5] For brief exposures, the American Conference of governmental Industrial Hygienists (ACGIH) set a short-term exposure limit (STEL) of 0.6 mg/m^3 over a 15-minute period. At a breathing rate of 9.6 m^3 per 8-hour working day, this equates to a recommended short-term limit on inhalation intake of 0.18 mg. U.S. Agency for Toxic Substances and Disease Registry (ATSDR), "Toxicological Profile for Uranium" (Washington, DC: U.S. Public Health Service, September 1999) p. 9 (hereinafter, ATSDR Report). "The STEL (i.e. less than a 15 minute exposure followed by periods of minimal or no exposure) would apply to the shorter term exposures occurring in the Gulf War (e.g., entering damaged equipment)." The Office of the Special Assistant to the Deputy Secretary of Defense for Gulf War Illnesses, Depleted Uranium in the Gulf (II) (Washington, DC, 2000) p. 19.

[6] Based on an 8-hour workday, 40-hour workweek maximum air concentration limit of 0.2 mg/m^3, with an average breathing rate of 9.6 m^3 per 8-hour working day. U.S. Agency for Toxic Substances and Disease Registry (ATSDR), "Toxicological Profile for Uranium." (Washington, DC: U.S. Public Health Service, September 1999) pp. 322, 329. The 2 mg figure applies for both soluble (type F) and insoluble (type S) compounds; N. Stradling et al, "Anomalies between radiological and chemical limits for uranium after inhalation by workers and the public," 105 *Radiation Protection Dosimetry* (2003) p. 177; Dr. Naomi Harley, statement to the Presidential Special Oversight Board for Department of Defense Investigations of Gulf War Chemical and Biological Incidents (Washington, D.C., 19 July 1999); The Office of the Special Assistant to the Deputy Secretary of Defense for Gulf War Illnesses, Depleted Uranium in the Gulf (II) (Washington, DC, 2000) p. 18.

[7] U.S. Code of Federal Regulations, 10 CFR 20, "Standards for Protection Against Radiation," Subpart C, 20.1201, "Occupational Dose Limits for Adults, 1 January 2001.

[8] The annual limit on inhalation intake is based on the volume of air that a worker is assumed to breathe in a year (2,400 m^3), and the occupational exposure limit of 0.2 mg/m^3. U.S. Agency for Toxic Substances and Disease Registry (ATSDR), "Toxicological Profile for Uranium." (Washington, DC: U.S. Public Health Service, September 1999) pp. 321, 329; U.S. Code of Federal Regulations (CFR), 29 CFR 1926.55, Appendix A, "Threshold Limit Values of Airborne Contaminants for Construction," Uranium, 1 July 2000.

[9] For brief inhalation exposures, the UK Health and Safety Executive (HSE) set a short-term exposure limit (STEL) of 0.6 mg/m^3 over a 15-minute period. At a breathing rate of 9.6 m^3, this equates to a recommended short-term limit on intake of 0.18 mg, based on chemical toxicity. UK Health and Safety Executive (HSE), *Occupational Health Exposure Limits 2000,* EH40/2000 (Sudbury, Suffolk, HSE Books 2000).

[10] This is the occupational exposure limit for soluble natural uranium compounds (0.2 mg/m^3), at a breathing rate of 9.6 m^3 per 8-hour working day, based on chemical toxicity. Ibid.

[11] This refers to an inhalation of type S (insoluble) natural uranium based on a 5 micron activity mean aerodynamic diameter. As noted above (see supra n. 8), the majority of DU particles created by an impact are insoluble. The limit for intake by inhalation of type M (moderately soluble) natural uranium is 430 mg/year; for type F (soluble) it is 1290 mg/year. N. Stradling et al, "Anomalies between radiological and chemical limits for uranium after inhalation by workers and the public," 105 *Radiation Protection Dosimetry* (2003) p. 176.

[12] The Royal Society, "The health hazards of depleted uranium munitions, Part I." (London: Royal Society, 2001) p. 5.

[13] Presidential Special Oversight Board for Department of Defense Investigations of Gulf War Chemical and Biological Incidents, "Special Oversight Board Analysis (Ver. 2) of OSAGWI"s DU Report," (Washington, DC, 19 February 1999) (in author's files).

[14] M.A. Parkhurst et al, "Depleted Uranium Aerosol Doses and Risks: Summary of U.S. Assessments," PNWD–3476 Prepared for the U.S. Army by Battelle (Richland, WA: Battelle, October 2004) http://www.deploymentlink.osd.mil/du_library/du_capstone/index.pdf.

[15] The Royal Society"s *central estimate* "is intended to be representative of the average individual within the group (or population) of people exposed in that situation." The Royal Society, "The health hazards of depleted uranium munitions, Part I." (London: Royal Society, 2001) pp. 6, 41–43. See also Annexe C of the Royal Society Report online at http://www.royalsoc.ac.uk/policy/du_c.pdf.

[16] "We calculated a "worst case" estimate using values at the upper end of the likely range, but not extreme theoretical possibilities. The aim is that it is unlikely that the value for any individual would exceed the worst case. . . . If even the worst-case assessment for a scenario leads to small exposures, then there is little need to investigate more closely. If, however, the worst-case assessment for a scenario leads to significant exposures, it does not necessarily mean that such high exposures have occurred, or are likely to occur in a future battlefield, but that they might have occurred, or might occur in future conflicts, and further information and assessment are needed." The Royal Society, "The health hazards of depleted uranium munitions, Part I." (London: Royal Society, 2001) pp. 6, 41–43.

[17] M.A. Parkhurst et al, "Depleted Uranium Aerosol Doses and Risks: Summary of U.S. Assessments," PNWD–3476 Prepared for the U.S. Army by Battelle (Richland, WA: Battelle, October 2004) Chapters 3, 4.

[18] M.A. Parkhurst et al, "Depleted Uranium Aerosol Doses and Risks: Summary of U.S. Assessments," PNWD–3476 Prepared for the U.S. Army by Battelle (Richland, WA: Battelle, October 2004) Chapters 3, 4.

[19] A.C. Marshall, "An Analysis of Uranium Dispersal and Health Effects Using a Gulf War Case Study," Sandia Report SAND2005–4331, (Albuquerque, NM: Sandia national Laboratories, July 2005) p. 59–60.

[20] Ibid, pp 59–60.

[21] It is assumed that "soldiers spend 4 weeks in an area, starting from the time it is contaminated with 1 g m^2DU; all the DU is respirable; and the soldiers" activities cause enhanced resuspension of the DU owing to normal heavy vehicle movements, but the soldiers are not undertaking digging, ploughing or clearance operations." "The central estimate is based on UK-like conditions. . . ." The Royal Society, "The health hazards of depleted uranium munitions, Part I." (London: Royal Society, 2001) p. 43, Annexe C.

[22] It is assumed that "soldiers spend 4 weeks in an area, starting from the time it is contaminated with 1 g m^2DU; all the DU is respirable; and the soldiers" activities cause enhanced resuspension of the DU owing to normal heavy vehicle movements, but the soldiers are not undertaking digging, ploughing or clearance operations." "[T]he worst case [estimate] is based on arid, dusty conditions." The Royal Society, "The health hazards of depleted uranium munitions, Part I."(London: Royal Society, 2001) p. 43, Annexe C.

[23] Alexandra Miller et al, "Transformation of Human Osteoblast Cells to the Tumorigenic Phenotype by Depleted Uranium-Uranyl Chloride," *Environmental Health Perspectives* (1998) 106: 469.

[24] Ibid., p. 470.

[25] A.C. Miller et al, "Depleted uranium-catalyzed oxidative DNA damage: absence of significant alpha particle decay." 91 *Journal of Inorganic Biochemistry* (2002) p. 251; A.C. Miller et al, "Genomic instability in human osteoblast cells after exposure to depleted uranium: delayed lethality and micronuclei formation." 64 *Journal of Environmental Radioactivity* (2003) p. 248.

[26] A.C. Miller et al, "Depleted uranium-catalyzed oxidative DNA damage: absence of significant alpha particle decay." 91 *Journal of Inorganic Biochemistry* (2002) pp. 246, 251

[27] A.C. Miller et al, "Genomic instability in human osteoblast cells after exposure to depleted uranium: delayed lethality and micronuclei formation." 64 *Journal of Environmental Radioactivity* (2003) p. 257.

[28] A.C. Miller et al, "Depleted uranium-catalyzed oxidative DNA damage: absence of significant alpha particle decay." 91 *Journal of Inorganic Biochemistry* (2002) p. 251.

[29] In 1999 the incidence of Hodgkin's lymphoma among U.S. residents was 2.8 per 100,000 people (3.0 for men, 2.5 for women). For men and women aged 25–29, the incidence was 5.4 per 100,000; for ages 30–34 the incidence was 4.1 per 100,000. L.A.G. Ries, M.P. Eisner, C.L. Kosary, B.F. Hankey, B.A. Miller, L. Clegg, B.K. Edwards, eds., *SEER Cancer Statistics Review, 1973–1999,* National Cancer Institute, Bethesda, MD, http://seer.cancer.gov/csr/1973–1999/, 2002. Incidence rates in other countries with forces that served in the Gulf War or Balkans are similar: Italy—3.62; The Netherlands—2.32; United Kingdom—2.26; Saudi Arabia—2.69; Kuwait—4.33; Iraq—2.10. J. Ferlay, F. Bray, P. Pisani and D.M. Parkin, GLOBOCAN 2000: Cancer Incidence, Mortality and Prevalence Worldwide, Version 1.0, IARC CancerBase No. 5, Lyon, IARCPress, 2001, Limited version available from: URL: http://www-dep.iarc.fr/globocan/globocan.htm, last updated on 03/02/2001.

[30] U.S. National Cancer Institute, "Information about detection, symptoms, diagnosis, and treatment of Hodgkin's disease," NIH Publication No. 99–1555, 16 September 2002.

[31] U.S. Institute of Medicine, Gulf War and Health, Volume 1, "Depleted Uranium, Pyridostigmine Bromide, Sarin, Vaccines." (Washington, D.C., National Academy Press 2000) p. 142.

[32] M. McDiarmid, et al, "Surveillance of Depleted Uranium Exposed Gulf War Veterans: Health Effects Observed in an Enlarged "Friendly Fire" Cohort," 43 *J Occup Environ Med* (2001) p. 998.

[33] See discussion of U.S. DU Program at end of Chapter 2.

[34] UK Ministry of Defence, "UK Gulf Veterans" Mortality Figures," August 2002. http://www.mod.uk/issues/gulfwar/info/gen_reports/mortfigs_jun02.htm.

[35] Statement of Lewis Moonie, UK Defence Minister, in response to Dr. Gibson, House of Commons Hansard Written Answers for 11 February 2003, http://www.parliament.the_stationery_office.co.uk/pa/cm200203/cmhansrd/cm030211/text/30211w04.htm.

[36] Original in Italian: *"Esiste un eccesso, statisticamente significativo, di casi di Linfoma di Hodgkin."* Istituita dal Ministro Della Difesa, "Relazione Finale Della Commissione Istituita dal Ministro Della Difesa Sull"Incidenza di Neoplasie Maligne Tra I Militari Impiegati in Bosnia e Kosovo," 11 June 2002, p. 21.

[37] Original in Italian: *"I risultati dell"indagine a campione svolta sui militari italiani impiegati in Bosnia e Kosovo non hanno evidenziato la presenza di contaminazione da uranio impoverito." Istituita dal Ministro Della Difesa, "Relazione Finale Della Commissione Istituita dal Ministro Della Difesa Sull"Incidenza di Neoplasie Maligne Tra I Militari Impiegati in Bosnia e Kosovo."* Ibid, p. 21.

[38] Original in Italian: *"Per le neoplasie maligne (ematologiche e non), considerate globalmente, emerge un numero di casiinferiore a quello atteso."* Ibid., p. 21. See also C. Nuccatelli et al, "Depleted uranium: possible health effects and experimental issues," 79 Microchemical Journal (2004) 332.

[The presentation by Mr. Fahey entitled, "Depleted Uranium and Veterans' Health: A Flawed Testing Process and an Undersized, Politicized Study Limit Evaluation of Exposure and Effects," dated June 28, 2007, is being retained in the Committee files.]

Statement of Hon. Jeff Miller, Ranking Republican Member, Subcommittee on Health, and a Representative in Congress from the State of Florida

Thank you Mr. Chairman. I believe it is very important for us to be holding this hearing on Gulf War exposures.

We cannot forget the sacrifices of veterans who fought in the first Gulf War and must be vigilant in our responsibility to provide for the health care needs of all service men and women who have put their lives on the line to protect our freedom.

It has been over a decade since the first Gulf War. Unfortunately, to date, neither a cause nor a single underlying disease process has been identified for a wide variety of medical problems that thousands of Gulf War veterans have suffered from.

Yet, the scope of Federal research on Gulf War illnesses is broad, ranging from small pilot studies to large-scale epidemiology studies involving large populations and major center-based research programs. Between VA, DoD, and HHS, the Federal Government has sponsored over 300 distinct projects related to health problems affecting Gulf War veterans and spent nearly $300 million on research relating to Gulf War veterans illnesses from FY 1992 through FY 2005, and, the research continues today.

However, because there was a lack of systematic baseline medical data and reliable exposure data, researchers have faced many difficulties and as a result many of the health concerns of Gulf War veterans may never be fully understood or resolved.

Of particular concern is the rate of ALS in the Gulf War veteran population. The relationship between military service and ALS should be aggressively investigated and the provision of health benefits for those suffering with this debilitating disease should be provided without question.

At today's hearing, we will review what is currently being done to address the health consequences of the Gulf War. We will also examine if lessons learned have led to subsequent improvements in deployment health monitoring and evaluations, recordkeeping research and health risk communication.

I appreciate the participation of all of our witness and look forward to the testimony. We will hear from several veterans of the Gulf War. Their unique perspective is extremely valuable to helping us avoid past mistakes and respond to the health needs of military personnel currently serving in the Global War on Terror.

Thank you Mr. Chairman, I yield back the balance of my time.

Statement of Hon. Cliff Stearns, a Representative in Congress from the State of Florida

Mr. Chairman,

Thank you for holding this hearing. I hope to hear from our panel what kinds of exposures our servicemen and women are encountering in Iraq and Afghanistan in this conflict, the possible connection these exposures may have to debilitating diseases, such as ALS, and the steps the VA has taken to meet this critical health problem.

In the mid-1990s, Gulf War Syndrome became the center of media attention, and the focus of fear by Gulf War veterans and their families. Clusters of undiagnosed, mysterious illnesses, as well as persistent, debilitating, and unexplainable symptoms began to surface. However, under the Clinton administration, the appointed "Presidential Advisory Committee on Gulf War Veterans' Illnesses," reported on December 31, 1996 that scientific evidence had not produced "a casual link between symptoms and illnesses reported by Gulf War veterans to exposure [to] pesticides, chemical warfare agents, biological warfare agents, vaccines, . . . infectious diseases, depleted uranium, oil-well fires and smoke, and petroleum products." This Advisory Committee also recommended that VA closely examine the relationship between wartime stress and "the broad range of physiological and psychological illnesses currently being reported by Gulf War veterans."

We now know that some of their illnesses were, as the report indicated, were often the result of psychological stress. Combat stress, a constant risk of warfare, is known to affect the brain, immune system, cardiovascular system, and hormonal responses. Therefore the stress could certainly have been a contributing factor to some of the symptoms and illnesses reported, although not all. Now it is believed by most medical experts that there was no unique Gulf War Syndrome, but rather a number of illnesses arising from numerous causes. The list of possible causes includes, but not limited to, the exposure to: Chemical and biological warfare; Depleted uranium dust; Infectious diseases; Medical measures used to protect against the threat of chemical and biological warfare; Multiple vaccines; Nerve agents too low to cause acute symptoms that can cause chronic adverse effects on nerve and immune systems; Pesticides; Toxic hazards, oil fires, smoke, petroleum products; and Sarin gas.

In the years since the war, a number of Gulf War veterans were developing ALS (or Lou Gehrig's disease). Cancers and impairments of the neurological, circulatory, respiratory, and reproductive systems have been studied for their links to exposures during Desert Shield and Desert Storm. Still, a substantial proportion of veterans' illnesses remain undiagnosed to this day.

I was here in Congress when we attempted to help these veterans who were suffering under these ailments. In the Veterans Programs Enhancement Act 1998, Congress required the National Academy of Sciences to review the available scientific evidence and determine whether there is an association between illnesses experienced by Gulf War veterans. Additionally, this law required VA to submit an annual report on the results, status, and priorities of research activities related to the health consequences of military service in the Gulf War to the Committees on Veterans' Affairs. The law also established VA authority for priority health care to treat illnesses resulting from combat during any period of war after the Gulf War or during any other future period of hostilities.

I look forward to hearing from our panels of witnesses about the progress that the VA has made in providing for these veterans, and also what challenges, if any, veterans are encountering when seeking medical care for their illnesses.

Thank you.

POST-HEARING QUESTIONS AND RESPONSES FOR THE RECORD

Committee on Veterans' Affairs
Subcommittee on Health
August 2, 2007

Brigadier General Thomas R. Mikolajcik, USAF (Retired)
1751 Omni Blvd.
Mt. Pleasant, SC 29466

Dear Tom:

In reference to our Subcommittee on Health hearing on "Gulf War Exposures" held on July 26, 2007, I would appreciate it if you could answer the enclosed hearing questions by the close of business on October 2, 2007.

In an effort to reduce printing costs, the Committee on Veterans' Affairs, in cooperation with the Joint Committee on Printing, is implementing some formatting changes for materials for all full and Subcommittee hearings. Therefore, we would appreciate it if you would provide your answers consecutively and single-spaced. In addition, please restate the question in its entirety before the answer.

Please provide your response to Cathy Wiblemo at the Committee. If you have any questions, please call 202–225–9154.

Sincerely,

MICHAEL H. MICHAUD
Chairman

GULF WAR EXPOSURE—OUTREACH

Response from Brig. Gen. Thomas R. Mikolajcik, USAF (Ret.)

2. **Outreach—**Effective outreach can be a great tool in ensuring that veterans from past wars are kept informed of any changes or developments that may occur in the years after the conflict. Sixteen years have passed since Gulf War One ended.

- Have the outreach efforts of VA diminished in the last 16 years and if so, how?

Answer: I am not familiar with the VA Outreach efforts and do not feel qualified to answer this question. My experience with the VA for my condition of ALS was very trying at the beginning. It took me over 2 years to be granted a service connected disability of 90% and another 5 months to be categorized with 100% disability. The time between appointments seemed excessive and the amount of paperwork was daunting. Once in the VA system, routine appointments are easy to obtain, however specialty appointments can take several months. It is very apparent that the caseload of veterans far exceeds the ability to care for them. Since 2003, category 8 veterans have not been seen because of budget limitations and staffing.

With regard to the care and equipment available, there is no one source which can lead you through that maze. The same applies to benefits and compensation. The individual veteran needs to research, ask questions and continually follow through for everything he needs. The unfortunate thing is that many veterans don't have the energy, skill or ability to research and follow through. Since my correspondence from the VA granting me 100% disability with accompanying documents, I have received no other outreach information updating me on any new programs or benefits. I've had a motorized wheelchair for 1.5 years and I just learned through a disabled veterans newsletter that I am authorized a small clothing allowance. When I was issued the wheelchair, why didn't the VA give me the appropriate form to fill out for the clothing allowance?

The VA has a robust website however, one must have a computer and understand how to navigate the website system.

- What would you do to change that? Is this a statement applicable to VA overall, suggesting that even with the Vet Center program VA does not have the capacity to treat veterans?

Answer: When veterans enter the VA system, they should receive a comprehensive briefing on their entitlements along with the pamphlet they now receive. Periodic mailings and group counseling sessions should be used to update veterans on changes. Funding by Congress must be increased in order for all veterans to receive proper and well deserved care. Our government helps people all over the world, yet many veterans at home are ill cared for and do not understand the benefits they are entitled to.

Committee on Veterans' Affairs
Subcommittee on Health
August 2, 2007

Anthony Hardie
National Treasurer
Veterans of Modern Warfare
1722 N. Sherman Ave.
Madison, WI 53704

Dear Anthony:

In reference to our Subcommittee on Health hearing on "Gulf War Exposures" held on July 26, 2007, I would appreciate it if you could answer the enclosed hearing questions by the close of business on October 2, 2007.

In an effort to reduce printing costs, the Committee on Veterans' Affairs, in cooperation with the Joint Committee on Printing, is implementing some formatting changes for materials for all full and Subcommittee hearings. Therefore, we would appreciate it if you would provide your answers consecutively and single-spaced. In addition, please restate the question in its entirety before the answer.

Please provide your response to Cathy Wiblemo at the Committee. If you have any questions, please call 202–225–9154.

Sincerely,

MICHAEL H. MICHAUD
Chairman

Questions for the Record
Hon. Michael H. Michaud, Chairman
Subcommittee on Health
House Committee on Veterans' Affairs
July 26,2007, 10:00 a.m.
Room 334, Cannon House Office Building

Follow-Up Questions for Anthony Hardie

1. ***ALS*—**Mr. Mikolajcik proposed in his testimony that a congressionally directed ALS Task Force should be established to help provide direction in ALS research and to develop a strategic plan to tackle this illness. The 30- 60- 90-day timeline he suggested in his testimony lays out some structural parameters.

- What are your thoughts on this plan and do you think that it would be effective, given the apparent stagnation in Gulf War research and treatment of the Gulf War illnesses?
- What do you suggest should be the top three goals of such a task force?

2. ***Outreach***—Effective outreach can be a great tool in ensuring that veterans from past wars are kept informed of any changes or developments that may occur in the years after the conflict. Sixteen years has passed since Gulf War One ended.

- Have the outreach efforts of VA diminished in the last 16 years and if so how?
- What would you do to change that? Is this a statement applicable to VA overall, suggesting that even with the Vet Center program VA does not have the capacity to treat veterans?

3. ***Treatment***—Mr. Hardie, you state in your testimony that "being seen is not the same as being treated".

- Could you go into more detail regarding that statement?
- Ms. Nichols and Mr. Hardie—have you found that the medical doctors that treat Gulf War veterans are ill informed?
- Mr. Hardie, you mention that many Gulf War veterans have given up going to VA. Do you know if they are going elsewhere or not going anywhere?

[RESPONSES WERE NOT RECEIVED FROM MR. HARDIE.]

Committee on Veterans' Affairs
Subcommittee on Health
August 2, 2007

Denise Nichols, M.S.N.
Vice Chairman
National Vietnam and Gulf War Veterans Coalition
500 Fifth Street NW
Washington DC 20001

Dear Denise:

In reference to our Subcommittee on Health hearing on "Gulf War Exposures" held on July 26, 2007, I would appreciate it if you could answer the enclosed hearing questions by the close of business on October 2, 2007.

In an effort to reduce printing costs, the Committee on Veterans' Affairs, in cooperation with the Joint Committee on Printing, is implementing some formatting changes for materials for all full and Subcommittee hearings. Therefore, we would appreciate it if you would provide your answers consecutively and single-spaced. In addition, please restate the question in its entirety before the answer.

Due to the delay in receiving mail, please provide your response to Cathy Wiblemo at cathy.wiblemo@mail.house.gov. If you have any questions, please call 202–225–9154.

Please provide your response to Cathy Wiblemo at the Committee. If you have any questions, please call 202–225–9154.

Sincerely,

MICHAEL H. MICHAUD
Chairman

National Vietnam and Gulf War Veterans Coalition
Washington, DC
October 2, 2007

Hon. Michael H. Michaud
Chairman
Subcommittee on Health
Committee on Veterans' Affairs
United States House of Representatives
335 Cannon House Office Building
Washington, DC 20515

Dear Congressman Michaud:

I am honored to respond to your written questions following the July 26 hearing on "Gulf War Exposures."

1. ***ALS—What are your thoughts on General Mikolajcik's thoughts on this plan and do you think it would be effective, given the apparent stagnation in Gulf War research and treatment of the Gulf War illnesses?***

The General hit it right on the mark! He clearly and briefly nailed the identification of the problem as a lack of leadership. I would like to say that this is also the problem overall with Gulf War illness. Leadership is suppose to identify problems, strategize the solution, the solution is then broken down into tasks with clearly defined timetables and project target goals, and then the plan is executed. Each project has an assigned individual that is held to accountability and responsibility. Leadership also is then held accountable and responsible for the success and failure of each component and projects individuals' actions or nonaction. Leader should be named as well as each subsequent project leader. Then Congress has to do their part of overseer and true Oversight and they have shared accountability and responsibility to the taxpayer to show results that get transferred to the clinical application of research and results on the large scale.

There is a lack of focus and direction in all medical research. The end result should be measuring the patient veterans' improvement in the clinical area. There are huge disconnects in the VA/DoD health system in this regard. We can effectively employ tiger teams to solve a battlefield problem and get research and equipment fielded in a somewhat timely and effective manner but we do not have this robust system in place for diagnosed or undiagnosed illnesses and chronic life threatening medical problems.

This is what is truly lacking in DoD/VA and the government (Congress and the Administration) actions' to the problem of exposures that occurred in 90–91 with Operation Desert Storm and the resultant health effects. The logs and reports that

would have given us the whole truth on exposures were destroyed (ordered by General Blanck and confirmed by GAO and the author Cy Hurst) and not one person has been held responsible for that destruction of government records that were critical to the health effects after the war. These logs and information would have given us the information to lead us quickly to what resulting health problems we would have seen in a timelier manner.

The actions to address Gulf War illness and resulting illnesses both diagnosed and undiagnosed show that our system of health care for veterans is broken and has been for a long time (example Agent Orange).

The government responded by funding research studies overwhelming on stress for 13 years while the veterans composed of all prior ranks were screaming and trying to get the truth out on exposures and how our health was rapidly deteriorating. There were not even annual hearings with the VA Committees with veterans (individuals) to identify to you what was reality! Veterans' health problems have led to broken marriages, inability to maintain their careers, and to the point of veterans aging family members (Moms and Dads) having to try to help these adult soldiers-veterans.

ALS thankfully was recognized as occurring in higher numbers in Gulf War veterans than should have occurred in a normal population. The VA is recognizing that but congress has yet placed this into a bill to make it legal! MAKE THE BILL/LAW happen within 30 days that ALS will be an Immediate Presumption with fast track priority and VA ratings accomplished within 30 days.

WE have asked for that several times. We now are finding Multiple Sclerosis in Gulf War veterans at a greater than expected level and no unified leadership or effort is being seen yet again. WE have Cancers and other diagnosed illnesses but no one has put the pressure on VA's Health area to share data to get the whole picture.

The General spoke clearly identified the problem and spoke to a solution on one area—ALS. Mike Donnelly (Major—F16 pilot died 2½ years ago) and Randy Hebert (Major, Marine) were brought forward by me to Congressman Shay's Committee years ago to testify. Other Gulf War veterans with ALS from earlier are Randy Hebert, Jeff Tack, and Tom Oliver. And we still can't give them much more than get them compensated. Well that is not enough! In addition, I am hearing that the benefits that they are entitled to in regards to nursing care and assistance, home improvements for their care, specialty equipped vans, and educational benefits for their spouse and children is not fully communicated to each and every one of them and means to get that assistance in a timely manner is not coordinated. All of this information should be readily supplied to them in writing and also easily assessed on the VA Web site. I contacted the Donnelly's because that family turned into true advocates. His dad a former marine and state legislator of Connecticut did everything he could for his son and all the others. Tom Donnelly and I talked over the general's testimony and the followup questions his comment to me is very revealing. I asked him if I could share it with you. His comment was that he doubted that the government would ever do anything useful. He felt that there would never be true effective action and that other entities outside the government would have to solve the problem. He also compared the Gulf War veterans of 90–91 to the past veterans of Agent Orange and the problem with getting any help now with so many of our current OIF/OEF casualties needing care. Mike and his wingman are now dead as are others. His comrades have formed 2 separate nonprofits in AZ that hold annual golf tournaments and awards dinners. Their purpose to look after the children left behind and to fund scholarships for those children. The Donnelly's still reach out to the other ALS veterans and assist them as much as possible. This family and the General need to be recognized by the CONGRESS for their unending efforts in supporting and leading the Gulf War Veterans with ALS.

The General was right with his strategic goals and timetable. Yes I support it wholeheartedly.

I would also recommend highly that the VA ALS registry be more public and include data on how many Gulf War veterans both deployed and non-deployed and risk factors with each. We need to know if anthrax or other vaccines may be causing this increase. We also need to have data re on where in theater each veteran with ALS was located and what was their duty and unit and what other exposures may be contributing to the development of this deadly disease. This data without exposing names should be public on a Web site so that researchers and the public can join in the battle to tackle the illness with ideas and information. The Gulf War veterans with ALS should be the lead cohort for any ALS study because they were previously healthy and we do have more health data in the military than normal individuals in the population. Also our duty as a nation should be to place the troops and veterans health as the priority. We also have the depository at DoD that has blood and other specimens on this group of veterans that should be allowed to be

used by non DoD/VA researchers to find answers NOW. I include a recent article on the depository at DoD that highlights this problem for your review. I also include one other article on cancer data not being reported from VA that is altering National Cancer data.

YES THIS PLAN SHOULD BE DONE AND WITH IT I THINK THE PROGRAM ON GULF WAR ILLNESS WOULD BE INVIGORATED BECAUSE IT WOULD SERVE AS A ROLE MODEL. I WOULD START RIGHT NOW IN THE SAME DIRECTION WITH AN MS GULF WAR VETERANS PROGRAM. THESE TWO PROGRAMS SHOULD BE OCCURRING CONCURRENTLY BECAUSE THEY ARE BOTH RELATED TO NEURO MUSCULAR AND POSSIBLE AUTOIMMUNE OR VIRAL SEQUELE TO NEUROTOXIC SUBSTANCES.

What do you suggest should be the top three goals of such a task force?

1. Separate ALS Gulf War Veterans from other veterans and civilians to use as a specialty Cohort.
2. Designate THREE VA HOSPITALS as specialty centers—ALS EXCELLENCE CENTERS. BE SURE that One is East Coast—One Central—One WEST Coast. Leadership overall should be named and each center should have named individual.
3. SET UP COORDINATION WITH CIVILIAN ALS CENTERS OF EXCELLENCE. SET UP UNIVERSITIES/CIVILIAN MEDICAL CENTERS IN EACH GEOGRAPHICAL LOCATION EAST—CENTRAL—WEST to be RESEARCH CENTERS OF EXCELLENCE WITH NAMED INDIVIDUALS.
4. Designated by name lead individuals in each government agency that will be involved.
5. Set up VETERANS and their support system for ALS at each regional VA–VISN as Task Force. SET up from each of those a national VETERANS ALS TASK FORCE.

The ALS situation is time critical and should go top down and down up along with lateral off spouts. The initial setting up is crucial and necessary support and communication should be considered as essential. The VA should be in direct communication with each of these veterans and families on a continuing and scheduled basis to follow up on their needs proactively. My complements to General Mikolajcik for his clear leadership and my prayers and concerns go out to each veteran and their family that has encountered ALS that this effort will rapidly succeed for them and alleviate their burdens.

My thanks to you personally Representative Michaud and to the House VA Health Subcommittee for highlighting the issue and having this hearing.

I encourage you to have other hearings on Gulf War illness, one on benefits delivery and one on Clinical Care. I offer my time and ideas and suggestions on these efforts.

2. *Outreach—Have the outreach efforts of VA diminished in the last 16 years and if so how?*

The answer is YES. The congress including VA Committees on both sides Senate and House and the Current Government Reform and Oversight Committee of the House has been absent. The need is for continual programmed Committee hearings to keep a focus on this issue and to provide oversight to corrective action and true implementing of the laws by the word of the law and the sense of the Congress.

There needs to be accountability and responsibility in action and not just words.

What would you do to change that?

The VA has failed to update clinical guidelines, to provide training to all VA hospital individuals, and the VA has failed to be sure that progress reports on funded all Gulf War illness research projects. There is a need for interim research findings at 6 month time periods and a final report of each research project finding and recommendations from each project. WE need this in an organized format that is communicated thoroughly. WE need all research project reports not just the published peer reviewed journal result because some of these projects that are funded are never published in peer reviewed journals. This extends to DoD research projects also. WE need the full 300 plus study white paper. Validate to the veterans and the taxpayers what they paid for over the last 16 years.

The VA has let lapse the newsletter for Gulf War illness and we no longer are getting them mailed to the veterans. These newsletters need to be on the VA website from each issue to the current in an easy to find format. The DoD has also fell down on the job since re-titling the area DEPLOYMENT Medical. The veterans nor the medical professionals receive updates on research projects and their findings and implications.

The VA hospitals have no signs up about the VA Gulf War Registry and information sources and the kiosks in each VA have no information on Gulf War illness.

The VA has lost focus for one of the largest veteran's populations that of those exposed to Hazardous toxic exposures. A significant effort must be made to rectify this situation. I made numerous suggestions during my House and Senate testimonies. I would suggest it is time for the Congress to step in and legislate that these actions occur and hold them responsible.

Mandate training, annual meetings, training and hiring physicians with toxicological, anti-aging, environmental medicine training, set up task forces at each VA hospital to include veterans, administration, and medical personnel to address concerns from Gulf War exposures and other eras (Agent Orange, atomic veterans, and project shad). Then institute regional and headquarters task forces set up to rectify the problems that have been created by the ineffective leadership at the VA in regards to Gulf War illness. Provide materials on hazardous exposures ie newsletters, training programs, update VA Web site to include this information, and provide video conferencing so that the VA RAC GWI meetings can be shared system wide for medical professionals, researchers, and veteran patients.

Registry exams must be available, and the specialty clinics we had set up early in 1994 need to be reestablished, and the WRIISC centers in DC and Orange, New Jersey need to be expanded to at least 3 more locations (South, Central, and West Coast). These WRIISC centers have a good reputation so far but referrals to them are not readily available and health care professionals have not understood their availability and funding was not set up for veteran patient travel.

There has also been concern that Gulf War veterans are being minimized and not fully screened on an ongoing basis because of lack of funds and the ability to meet the need of younger veteran population from OIF and OEF, Gulf War Veterans, and all the other veterans due to staffing shortages.

There is also a potential problem with veterans not being able to access eye exams and dental exams unless they are rated at 100%. These vital body systems are affected by hazardous exposures and those huge factors to health are being totally neglected and no data even available.

Two new advisory Committees need to be implemented for Gulf War illness one on clinical care and one on benefits. The VA GWI identified the need to the Secretary of the VA months ago and no action occurred so therefore Congress must step up and legislate these to be formed in somewhat the same as the VA RAC GWI.

I would suggest more veterans to be at the table and only one VSO at a time to serve and at least one family member to also be included. Then specialists on benefits will be needed for the benefit advisory committee.

Then health care professionals in and out of the VA system for the clinical care advisory Committee. This committee must interact with the research advisory Committee in order to be able to take the research findings and implement them throughout the VA system. This clinical care Gulf War illnesses advisory Committee should include experts in the area of anti-aging, environmental medicine, and toxicology. The key here is to have interaction with each hospitals' task force locally and with regional task forces. So issues can be shared and worked at different levels. The chair and co chair must have management business skills and communication people skills to set long and short term goals and move toward resolution of problems. There must be commitment from the VA Administration and from both the congress and the President to move the VA forward into the new century where consumer client veteran patients feel there is a commitment and is evident through actions.

I would suggest to initial start with Gulf War illness and Gulf War veterans as these prove successful then Agent Orange, Atomic Veterans, and project shad advisory Committees need to be started.

The VA health division needs to set up databases that collect diagnosis information for Gulf War veterans—cancers, all diseases. This data needs to be reported semiannually to the veterans, to congress, to civilian medical organizations and needs to be available on a Web site. Registries for MS, cancers, other diseases, birth defects should be manned at each VA hospital, each regional VA center, and then to the health division. A death registry that contains name, age, cause of death, unit assigned in the Gulf War would be invaluable in honoring our veterans but also provide researchers data on deaths of Gulf War veterans. These registries must be public and transparent on the VA Web site. One of the articles I am enclosing talks about cancer data from the VA not being shared. This quarantine of information must immediately be stopped.

Bills currently introduced by Representative Pelosi and Senator Clinton, H.R. 3643 and S.B. 2082 must be reviewed, supported with some changes, and made into law before the end of this congressional session. Veteran data needs to be collected

from the civilian side of house also because not all veterans can or do utilize the VA. Death records in many states do not record Veteran service or war in which they served unless they have a VA file number. Birth records need to record parents and grandparent service and war time service to be complete in regards to hazardous exposures. Our data on birth defects can not be judged to be total and complete until all states have birth defect registries that also include a means of documenting health issues that arise after birth an example is autism, learning disorders, or health defects found later after birth. There must be some thought to how to add current information to existing records.

The whole process of VA contracting with the IOM for exposure relationships to establish presumption of connection must be totally revamped. Due to the IOM process the adversarial position of the veterans begins. I suggest a simplified approach of comparison of veteran population with age and the general population data that is already available and updated regularly to be utilized. If veterans are showing increases with known diseases that are above a random occurrence then that disease needs to be presumed service connected within 60 days. I encourage the government reform Committee and VA Committee hold joint hearings and investigation into this area of concern.

There must be a revamping of the VA benefit claim process now. It is a black mark on this nation to treat its veterans as it has over the last 50 years. To have sick veterans with cancers and other diagnosed illnesses that are probably connected to their service exposures die without any assistance from their government is wrong. To leave their spouses to start the process all over and to continue the battle is wrong. This adversarial process impacts the belief of the active duty and reserves when they agree to serve. It impacts prior service families from encouraging their offspring to serve their country thru military service.

Only through going through each of these steps and showing transparency and a full commitment will the faith of the veterans, their families, and the public be restored.

Through these efforts and more that faith to trust the government will be healed and recruiting for active duty and reserves will benefit because the promises will have been restored.

Only through all of these efforts will our Nation be ready to deal with environmental exposures from WMD and WTC health concerns. The military medicine in the past led the way as examples in the implementation of the best care techniques for gun shot wounds and rapid air evacuation that has impacted civilian medical practice that has saved lives. WE can do this again with changes now in policy changes in relation to Gulf War illnesses.

Is this a statement applicable to VA overall, suggesting that even with the Vet Center program VA does not have the capacity to treat veterans?

I think the Vet Center program is a needed program and needs to be continued. I will suggest that you contact others with more expertise in that area to have suggestions for improvement. I do feel that there is newer breaking research in the area of PTSD treatment that the Vet Centers specialize in that needs to be brought to the Vet Centers and implemented across the country rapidly to meet the needs of the returning OIF/OEF veterans. I believe that civilian counseling should also be set up for active duty, Reservists, Guard members, and veterans so that this overwhelming need can be met in a timely urgent means. I also feel that advisory group on PTSD should be initiated and ongoing until the problem is resolved. I also feel the need for local, regional, and central task forces that involve the veteran client, family members, and experts would help facilitate the revamping, communication, and upgrading in this area as in the clinical area would be beneficial.

I do not think it is time to dismantle the VA, veterans do have unique needs and have the most unusual social, emotional, and physical networks that were formed in service to their country. They have unique management, organization, and leadership abilities that need to be tapped and utilized to correct the problems. The ability to blend in civilian experts and facilities exists and we have seen them reaching out so help facilitate and make it happen.

As you can see there are needs for the Committees to have more hearings and joint senate and house hearings would be most effective to get the facts and let the veterans be heard and be a part of the process that will benefit them and future veterans. The need for committees to ask for insightful written and oral testimony with suggestions for what can be done on the legislation, administration, clinical care, and benefits can not be overstated. The need for good questions both at the hearing and as follow up is extremely important. The need to have FULL Committee Hearings outside VA in possibly six locations throughout the country (divide the country line from North to south and then intersecting with east-west lines then

pick center geographically for 6 locations) would be beneficial to the veterans and to you the Committee Members.

The Committees also should consider assisting financial for veterans in regards to airfare and hotels for these hearings. Veterans do not have an excess of funding to participate and be witnesses.

3. ***Treatment***

Being seen is not the same as being treated and have you found that medical doctors that treat Gulf War Veterans are ill informed? Are Gulf War veterans giving up on going to the VA, going elsewhere, or not going anywhere?

YES DOCTORS ARE ILL INFORMED. They are also restrained by policy whether written or unwritten that began when we returned from the Gulf War in 90–91. The doctors are not allowed to have an inquiring mind to find answers. The example I gave on the research I provide the doctor at the VA on Hypercoagulation in Gulf War Veterans and treatment suggestions is my most graphic example.

When I found out that the doctor had not followed up on contacting the doctors and authors of the paper and refused to retest or provide treatment to me or other Gulf War veterans and instead offered me a psychology consult, was the insult that pushed me not to return and to seek answers and treatment elsewhere. When the doctor, told me her hands were tied even prior to that visit, I knew that what other veterans and the doctors that tried to do the right thing within the VA and then were told to not see Gulf War Veterans or were cut from the staff at VA hospitals were saying was true. When I found out the editor of the journal that published the independent research on Gulf War veterans with hypercoagulation worked at the VA Hospital Denver Lab it just was over the top. It showed me that they were not listening to find clues and help in testing and treating Gulf War veterans. Other items I witnessed and experienced are many and I will try to make this as short as possible. First of all exams where not to a high standard. I was a nurse with a Masters Degree and varied clinical and teaching experience in the military active duty, reserve duty, and civilian positions which included teaching nursing. When I had been taught Clinical assessment we used the same physical assessment textbooks as medical students and this was in the mid 70's. The neurological physical exams that should have been very thorough and looking for changes when it was known we were exposed to neurotoxins and a mixture of exposures was very limited. Dr Bill Baumzweiger is an expert to be consulted in regards to his exams and what he found. The comments I had at the VA were gee you are complaining of a skin rash you need to see a dermatologist and then when I asked to see one they said no you will have to go to a civilian this was during the initial CCEP at the VA. I had to push for any follow up for the ringing in my ears that continues to this day. I was never referred to neurology, infectious disease specialist, endocrinology, or immunologist.

I also participated in the DoD CCEP at Fitzsimmons USAH, Denver. The person doing EEGs noted to me he was seeing abnormalities with each of the Gulf War veterans I never got my report on my own test results. WE veterans have not seen the compilation of all those exams that were done. I did have the hearing tested by an audiologist that had been hired back at Fitzsimmons, he did the air percussion testing to the ears and he was puzzled and had me return to be retested at that time we got into a discussion I asked him if it was hearing lost from noise since I had been a flight nurse on C–130's and had been exposed to constant generator noise during the war. He said no, I said what is it then and he said he saw signs indicating ototoxicity. I at that time showed him the full Senator Reigle report at which point he got very interested and wanted to keep the copy I had shown him which I willingly gave to him. I had taken no chemotherapy, antibiotics, or aspirin or any other item that would cause this damage except exposures in the Gulf War.

At the dermatology clinic I was seen by a female fully qualified dermatologist that was very interested in my rash. She documented it but said she had to have me released by the chief of service. He came in and blamed it on age and psoriasis. After he left, she shut the door and wanted to talk. She was a West Point Graduate and her husband had served in the Gulf with us and was experiencing the symptoms we all had. She asked me for any and all information I could share with her. Within 2 weeks I returned with copies of everything from hearings on the hill, to information on CFS and MCS and presented it to her. Well later I found out from a Veteran (first SGT Army) from KS that was there getting tested that this same DR had been seen flying into the office of the Dr that was in charge of the CCEP at Fitzsimmons right in front of him waiting to see the same Dr. He recounted to me how upset she was in her verbal encountered with this chief DR. This was the same chief doctor I had heard about from soldiers at Fort Carson that were being

seen in the Medical Hold unit. Extensive vision testing was done at Fitzsimmons that I never received copies of to include in my record. Again the veterans that participated in these extensive testing have never seen the compilation of all the exam results on all of us. EMG's were also done and again the doctor was curious and asked for any information I could share. Again no copies of the results and again no compilation of these results on all of us Gulf War veterans has ever been seen. When you left the DoD CCEP after cognitive testing and all the other testing you felt they knew more than they were telling. I witnessed and spoke to veterans that were being told it was all in their minds or that it was because of their age, this was despite the fact that these were young soldiers in their 20's. I witnessed disparities in the testing that was done on some veterans and not others. I confronted the chief doctor that he was not being honest as a doctor should be after that I was subject to his harassment that was witnessed by the other veterans that were there being seen and staying at Fitzsimmons since they came from a number of active duty bases. I supplied notebooks of hearing documents and materials related to questionnaire for Ross Perot investigation for these soldiers to have in their dayroom. I supplied the copying and the notebooks at my own cost and the troops were very interested in reading them. The only problem is they kept vanishing and the specialist that was there to schedule the exams finally confided in me that the chief doctor kept taking them away.

The last item of interest is I would see these same military doctors appear at the VA in civilian clothes in white lab coats seeing the Gulf War veterans there.

The veterans that were also Vietnam veterans as well as Gulf War veterans were very jaded and told me the system would never change. General Horner who I saw at the tenth anniversary of the war hosted by the Kuwaiti Ambassador told me in front of another Gulf War veteran they just didn't realize how bad the system was broken. In Pueblo, Colorado we had an Army Reserve doctor who had served with us that would see Gulf War veterans in his civilian practice and was trying his best to help other veterans accurately documented their cases to the VA. He too eventually ended up to ill and had to retire from practice. The last time I saw him was in Phoenix AZ at the Environmental Medicine meeting where he had suck in since he didn't have funds for registration and was trying to gather information. At that point I introduced him to Lea Steele and Jim Binns of the VA RAC GWI. I also introduced them to Dr. William Rhea and had Dr. Rhea verbally telling them how he had approached the Secretary of the VA in 1990–91 to offer assistance and to train VA physicians on the care of the environmentally exposed. He was turned down. This is interesting since he had served as chief of Thoracic surgery at the VA Dallas before he started into environmental medicine.

Through independent testing with Hemex Labs, AZ and Immunoscience Labs, Calif and other labs I have found answers on my own condition. This testing needs to be done for all Gulf War veterans and would definitely help us get answers and treatment in the right direction started. I also had arterial and venous blood oxygen testing done and the results of that simple test was also enlightening but how many other Gulf War veterans have had that testing that showed the body was oxygenated but the transfer of oxygen to the body was being interfered with resulting in high venous oxygenation. These are the clues in blood testing that the VA should have been exploring all along.

But despite getting some answers I am still not receiving any consistent clinical care and most definitely not from the VA. The VA has caused a lot of the PTSD since our return from the Gulf War. It is simply exhausting when you are ill to have to keep pushing and explaining to doctors and hoping they are listening so most Gulf War veterans sit back quietly surviving and looking for supplements from Vitamin Cottage that might help.

This is a disaster, as a nurse and Gulf War veteran with years of practice and training I have focused on identifying the problems, giving voice, collecting data, going to hearings, commissions, IOM, and VA RAC GWI, coming to the hill and briefing staffers since 1994, working closely with Congressman Shay's Committee staff through the years of hearings he conducted, working to get cosponsors on each of our Gulf War veterans legislation efforts, talking and discussing with researchers what they are finding and what their thoughts are and sharing with them any information that would help them, and providing information to Gulf War veterans and asking the veterans for continuing updates from them. I have tracked research findings, searching for connections and future ideas for researchers. I have compiled obits for our own death registry.

I am upset that pro active screening for cancers and other diagnosed illnesses is not happening for Gulf War veterans.

I decided to deal with the government at the highest level to push for change as long as I can. After all we had been called whiners, were not believed, hit the policy

from up high not to reveal all the exposures the Gulf War veterans know about, and from doctors that told us their hands were tied. Many veterans are not being seen at all and have lost faith.

The question is will the policy and changes be made now or ever?

Additional Thoughts on Research:

Research needs to feed into changes in clinical care for Gulf War veterans now and continuously. Researchers need to finally be briefed on all the exposures that occurred. DO not spend money into research alone or we will all die without having received any benefit of this taxpayer spent money. Do put the funds into the DoD CDMRP program where consumer advocates serve on the review panels.

Do find a way to provide chromosome testing ie SKY testing (attachment provided) that will clearly show the highest level of proof of damage to the Gulf War veterans. WE veterans all deserve at least that testing so veterans that still wish to have children can have tests results that may affect their ability to have healthy children. We deserve that test to prove once and for all the damage done.

I am including the two articles I mentioned in my answers above and my written invited testimony to the Senate VA Committee along with my point paper that lists problems and solutions that I had done for the VA House Committee hearing for you to review.

I stand ready to assist you, Members of the Committees, and other Members of the Congress with help in whatever you may need be it more information, suggestions, suggestions of experts and veterans to bring forward, assistance in organizing, etc.

I apologize for the length of the answers to your questions but I strive to answer completely with definitive action ideas.

Respectfully submitted,

Denise Nichols, MAJ, USAFR (ret), RN (ret), MSN
Gulf War Veteran Flight Nurse
Vice Chair

Eight attachments follow.

Attachment 1

VA Cancer Data Blockade May Imperil Surveillance

By Michael Smith
Senior Staff Writer, MedPage Today

LOS ANGELES—Stonewalling by the Veterans Administration is putting U.S. cancer surveillance and research in jeopardy, according to many of the researchers involved in those fields.

After decades of sharing data freely and allowing researchers to get in touch with its patients, the agency has been blocking such activity for the past several years, according to Dennis Deapen, Dr.PH., of the Los Angeles Cancer Surveillance Program and the University of Southern California.

The result, Dr. Deapen said, is that California state data on cancer incidence rates are being skewed. And that, he said, is likely to have serious effects on national data.

The California Cancer Surveillance Program has seen a sharp drop in the agency's reporting of new cases to Californian cancer registries beginning in late 2004—from 3,000 cases in 2003 to almost none by the end of 2005, according to an article in the September issue of Lancet Oncology.

But the problem is not restricted to California, according to Holly Howe, Ph.D., of the North American Association of Central Cancer Registries (NAACCR) in Springfield, Ill.

"California has been very energetic in evaluating the impact of the loss of VA cases on completeness and the ability to produce accurate incidence data," Dr. Howe said.

"But it's not just California—it's nearly every state," she said.

However, California and Florida—where VA reporting of cancer cases has also been blocked—have large populations of veterans and large VA medical facilities, she said.

Missing data from those two states has the potential to warp national estimates, she said.

Lancet Oncology quoted Raye Ann Dorn, the VA's national coordinator of cancer programs, as saying that only California and Florida were withholding data, mainly because of privacy concerns.

Dorn was not immediately available for comment on the eve of the Labor Day weekend.

Lancet Oncology said other VA officials pointed out that of the 130 medical centers that collect cancer data, only 29 withheld cases from state cancer registries in 2006.

But the journal also said that, according to CDC data, VA centers in seven states are not reporting cancer cases and in six others, at least one VA facility is not reporting.

All told, "40 000 to 70 000 cases are potentially missed nationally each year," the journal quoted a CDC spokesman.

Dr. Howe said her organization and others have been trying to persuade the VA to resume wholehearted data-sharing, but with little success. "We've been trying to solve this for over 5 years," she said.

Asked if she knows what's behind the policy, Dr. Howe said flatly: "No."

Representatives of a "whole cadre of associations"—including NAACCR, the CDC, the American Cancer Society, and the National Cancer Institute—met in early August to discuss the issue, Dr. Deapen said.

He said the VA position has two main effects.

The skewing of national and state cancer incidence rates, he said, is "correctable."

"The VA still has the data," he said. "They could hand it out and then we could correct incidence rate data."

What is "incorrectable," he said, is the effect the data blockade could have on research.

Dr. Deapen said, for example, that researchers investigating the causes of a particular type of cancer might be misled if they were not aware of a cluster of cases being treated in VA hospitals.

"Once that study is done, (the researcher) doesn't get to go back and do it over," Dr. Deapen said. Research during this period "will forever require an asterisk" to remind other researchers that it might not be correct.

But even when states get VA data, some cases may slip through the cracks under a related VA policy that forbids interstate data-sharing, he said.

For instance, he said, it's common for veterans in some eastern states to seek treatment in neighboring states.

The host state doesn't count them, because they live next door. And the VA refuses to notify the home state or let the host state do so, so that some cases are simply never counted, Dr. Deapen said.

Several of the cancer registries that are being locked out of VA data take part in the Surveillance Epidemiology and End Results (SEER) program, according to Brenda Edwards, Ph.D., of the National Cancer Institute, which operates the database, a valued resource for epidemiological research.

"This will significantly impact reporting in SEER," Dr. Edwards told Lancet Oncology.

The collection of disease incidence data is a state responsibility, Dr. Deapen said, but the VA—as a Federal agency—is under no obligation to comply with state laws.

Nonetheless, for years the VA voluntarily shared its data and allowed access to patients, he said.

"We had it right and we were doing a good job," Dr. Deapen said. "Now we need to get back on track."

Primary source: Lancet Oncology

Source reference: Bryant Furlow. "Accuracy of U.S. cancer surveillance under threat." Lancet Oncology 2007;8:762–63.

Attachment 2

A MILITARY MALPRACTICE

Serum Samples From Service Members Go Unanalyzed. Battlefield Doctors Are Unable To Access Records. Who's Tracking The Troops?

By REMINGTON NEVIN August 26, 2007

The Department of Defense is failing to properly monitor the long-term health of soldiers, airmen, sailors and Marines more than 15 years after the outbreak of mysterious Persian Gulf War illnesses.

Following the first Gulf War, the Defense Department began collecting millions of serum specimens from service members returning from deployments, and placing

them in large freezers for future study. If thawed, this serum—which was bled from service members teaspoons at a time—would total thousands of gallons.

But to help the service members, someone would have to study these specimens, and that is rarely done. Although it houses the largest inventory of serum specimens in the world, the Defense Department repository employs only one full-time scientist and has never been awarded a permanent budget to test specimens for toxic exposures or other health threats.

The repository also is running out of space—bursting at the seams with more than 42 million specimens. More than 5 million of the repository's oldest specimens—collected before the Gulf War—are now stacked floor to ceiling in teetering cardboard boxes, inaccessible to researchers, while the Defense Department's health leaders slowly discuss how and where to build a new repository facility and who would run it.

The inventory continues to grow at more than 2 million specimens annually. Millions more specimens from the Gulf War era will need to be boxed up later this year.

And while leading civilian repositories now store frozen serum specimens in ultracold minus-80-degree Centigrade storage to minimize degradation, the Defense Department continues to store its newest serum specimens in outdated walk-in freezers at a comparatively balmy minus-30 degrees Centigrade, potentially harming the delicate protein and chemical biomarkers that might contain evidence of toxic and infectious exposures.

Urine specimens are another useful tool in monitoring health, as any doctor will attest. Yet the Defense Department discards the 2 million-plus urine specimens it collects every year during routine drug testing.

Monitoring health also requires access to modern medical records systems. Military hospitals in Iraq and Afghanistan are forced to use relatively archaic systems that don't communicate in real time with the rest of the electronic medical record. These systems don't even talk among themselves.

Doctors treating patients transported between facilities on the battlefield often can't access electronic records written by surgeons minutes earlier. Frustration has been so intense that doctors treating patients evacuated through Germany have developed a separate Web-based system to work around the problem. Confusion over which system the doctors in the field are supposed to be using continues, compromising the quality of the health data.

One solution, off-the-shelf Web-based technology—such as VPNs (virtual private networks), used commonly by corporations to allow remote access to computer networks—has yet to reach the battlefield. Service members stationed in Afghanistan on remote snowy mountainsides routinely access their personal e-mail on the Web, but medics are not empowered by the Defense Department to use the Web to view and interact with vital medical records stored on systems in the United States.

Instead, medics in the field are instructed to record medical information using outdated handheld computers that often break down or run out of power. More often than not, medics simply don't use them, leaving no trace of medical care and giving the impression of a falsely low rate of disease and illness among deployed troops.

Despite these problems, the Defense Department reassures Congress and the American public that service members have their health comprehensively monitored, including a lengthy reassessment a few months after they return from deployment.

These assessments are little more than poorly worded, multi-page forms of little use to clinicians and epidemiologists in screening for diseases. The reassessments have demonstrated little efficacy in increasing access to military mental or physical health care. They often distract doctors, nurses and other health workers from providing therapeutic patient care.

And now the requirement to complete this lengthy reassessment form is being waived for soldiers sent back into the war zone after serving more than a year there. Tragically, these overworked service members—the ones who need the most careful physical and psychological assessments—are often deploying again after completing a token two-page form containing only a single mental health question. Often, no one confirms both the accuracy of the information and the suitability of the service member for repeated deployment.

Because of this, large numbers of service members on psychoactive medications are still being deployed, including many on anti-psychotic medications and anticonvulsants. As many as one in seven deployed service members has a recent history of psychoactive medication use.

But just which of these deploying service members have potentially serious psychiatric disorders is unclear, because the data systems that monitor pharmacy prescriptions are not linked to the Defense Department's deployment database.

Nor are these linked to the larger medical surveillance database that tracks medical diagnoses. The Defense Department would be hard-pressed to quickly identify the service members deployed this year with a history of treatment for bipolar disorder or psychosis—in direct violation of its new policy.

What isn't monitored can't be measured or reported. Nor can it improve care to service members, or forecast what will be needed to care for the next generation of veterans.

The health data in the Defense Department's databases and the serum repository have shed light on possible causes of multiple sclerosis, schizophrenia and various cancers, and contributed to our understanding of the epidemiology of mental and physical diseases. But so much more could be done.

Sadly, many key military health organizations are led by careerists with little experience in this type of work. There is little incentive, and significant risk, for Defense Department health leaders to point out problems, to explore controversial findings or to contradict military leadership when the health of service members is at stake.

Monitoring the health of service members is a responsibility too important to be left to a military leadership distracted by the exigencies of war. Responsibility for monitoring health should be consolidated under a new Armed Forces Health Surveillance Center, under the direction of an independent civilian expert in public health. Service members cannot wait another 15 years.

Capt. Remington Nevin is a Johns Hopkins-trained Army public health physician currently serving in Afghanistan. His opinions do not reflect those of the Department of Defense.

Attachment 3

Testimony of Montra Denise Nichols, Major, USAFR (ret)
Vice Chairman National Vietnam and Gulf War Veterans Coalition
to the U.S. Senate Veterans Affairs Committee September 25, 2007

Hearing on Gulf War Veterans Illness Research

Thank you Senators for having this important hearing today related to Gulf War Illness and Research for the Gulf War Veterans of Operation Desert Storm 1990. It has been since 2000 since your last hearing on this issue. During the intervening 7 years, some small progress has finally been made in getting research moving in the right direction. It has been too long in coming and a major effort is needed starting now to make up for lost time. No progress has been made in improving the health of ill veterans. The majority of us are still waiting for definitive diagnosis and any effective treatment for our exposures. There is an overwhelming desperation that has developed year by year. We veterans feel betrayed and abandoned. We are angry at the lack of truth, accountability, and responsibility from our government. This is a National Security Issue because the way veterans are treated when they return directly has and will reflect on armed services recruitment. Funding for a war and the aftermath of exposures in war should be considered as a total. Needs of veterans of exposures in war are not to be considered as an afterthought!

I am not a constitutional lawyer but a citizen, former nurse, and affected Gulf War veteran and this is how a majority of Gulf War veterans view what has happened: We have seen this pattern through the years both from the Democratic and Republican Party and this has to stop now. Section 8 of the Constitution states clearly one of the duties of congress is to "raise and support Armies and militia." There are a lot of appropriations and authorizations that occur that are not called for in section 8 and Veterans that have been exposed to hazardous toxins should not have to beg and fight their own government for years and decades after exposures in war! Our needs should be addressed as the priority not as an afterthought or not to be balanced and compete with items not covered in section 8 of the Constititution!

As of the May GWVIS report from the VA we have 212,867 claims have been granted out of 696,842 that served in combat in Operation Desert Storm. This figure is getting close to ⅓ of the force. We have more than 175,000 with Gulf War illness than the VA study picked up. We also have 13,517 veterans that have died according to the GWVIS data. WE the veterans are concerned if this count is accurate because it does not match the statistics in their own report (GWVIS) of the number that have served and the number of estimated living veterans. These are not just numbers these are human beings that served and put their life on the line. Today I am handing in to you the obituaries we have collected, this three ring notebook containing 800 pages of 1,473 have been researched over the last 6 months and we

have thousands more that we are currently working on using a rigorous process of verifying and posting using copyright guidelines. We do not have all of them but what is interesting is to review the age of death and one can see clearly something is definitely wrong and we needed help from the time of exposure.

One of the Gulf War Veterans that died this month is Colonel Dr. Gil Ramon. Colonel Gil Ramon had five degrees, served in law enforcement in Wichita, KS as the youngest person at the time to attain the rank of Sergeant in the Sedwick County Sheriff's Department, served as the Assistant Vice President for Academic Administration at the University of Northern Colorado from 1975–1977, served as the Regional Director of the Denver, Colorado office which covered a six-state region served as an undersecretary in the Department of Education, served as Deputy Assistant Secretary of Operations, in Washington, D.C., named Executive Director of "The White House Initiative on Educational Excellence for Hispanic Americans," served as Deputy Commander of the 311th Evacuation Hospital, Army Medical Service Corps, Operation Desert Storm, where he served as Chief of Operations, U.S. Army Central Command, the Persian Gulf. Colonel Roman provided administration and operations guidance in the administration of a combat filled hospital (400 bed augmented). He was a remarkable person, when he testified before Representative Shays' Committee he did not let a massive nose hemorrhage that occurred while he was testifying stop him, only Representative Shays could do that by ordering a break in the hearing so that he could get it under control, clean up, and then continue his testimony. But most of all he and I were a team trying to help our fellow veterans of the Gulf War in Colorado by doing whatever we could including writing white papers for our Colorado delegation and candidates for office. He was my friend and I dedicate my testimony today to him and all of these hundreds of thousands of dead and living but injured veterans. I include his obituary as an attachment to represent one of tens of thousands of our lives that are no longer with us. His private cardiologist later wrote: "What is clear is that he [Colonel Roman] served in the Middle East and that he was a cardiomyopathy. I would submit that this may well be part of the Gulf War Syndrome."

Our Special Forces commander in Desert Storm died in July, General Wayne Downing, his death is connected because of immune system deterioration from exposures that is happening to all of us. I ask you how long do we wait. How many must pay with their lives and their quality of life before full attention and funding to fight these deadly exposures. This is the biggest black mark on our country ever! It is the largest post war casualty and morbidity ever in the history of this country! It has been worse because of policy and delay and denial techniques employed by all in the government that started with the atomic veterans and has continued through over 50 years. This is the same government that we veterans swore to defend! Everyone from the President to the Congress to the DoD and the VA from the past years has not shown the leadership and commitment that we deserved.

If you are going to fund the continuing war then you must fully fund the needs of the veterans, we refuse to be an after thought or disposable GI's. We also believe you should consider this war that started with us in Operation Desert Storm and has continued through Operation Iraqi Freedom and Enduring Freedom as one. You must address all legislative needs of Operation Desert Storm as you address the current troops and veterans. Our voices are united in that point. We also fully believe that Veterans of Agent Orange, Atomic Veterans, Anthrax vaccine veterans and Project Shad fall within the same domain of Environmental Exposures. What we find thru our push to breaking science in medical research for diagnosis and treatment will reach backward as well as forwards.

It has been 16 years almost 17 years since our health was affected in Operation Desert Storm. One of the initiatives that we as veterans and advocates have started is the Web site www.honorthenames.com. It is a shame and disgraceful that the VA can not provide the basic death data that we have asked for to include Name, Rank, Unit assigned, Age, and cause of death to be on a public registry online. At least if this data was available patients, doctors, nurses, and researchers could be more informed and possibly be more aggressive in follow up for our living veterans whether it be more focused efforts to screen for cancers, cardiac, or renal problems. I recommend this become a legislative effort to make this into a bill and then into law. Included in this bill would be a mandate that death certificates list if the deceased was a veteran and what war or time period they served. Currently many states' health departments would only know if the deceased was a veteran if a VA file number is indicated we need this uniform across all 50 states. If we can publish the names of those killed in Iraq then we should have the same for veterans that served at the beginning in Operation Desert Storm. If the VA can not do this, then write a bill/law that the Social Security Administration will do it. It is not appropriate to wait for periodic death mortality studies when this information can be of clinical

significance. If we have a higher rate of automobile accidents then this should be investigate and information given to veterans and their family members. The memory problems, cognitive problems and vision problems impact on auto and truck-drivers and also pilots.

On the same subject of data sharing we need data on all diagnostic codes be it ALS, MS, Seizures, all types of cancers, cardiac, renal, liver disorders from the veterans health care data for the Gulf War veterans at a minimal of annually again to be on the VA website open to all to review for the purpose of providing data that could show trends that need to be monitored for all Gulf War veterans in the clinical setting whether by the VA or civilian health care providers. Having been a practicing nurse, patient educator, critical care provider, and educator I know this data would be useful not only to health care providers but to the patients. This data would be as useful as the patient family history and past medical history in evaluating a patient's health risks that all health care providers use in educating and screening patients for other medical conditions that are likely to emerge. The veterans have already started unofficial registries by online email groups for MS, ALS, Parkinson's, Cancers, Cardiac problems, and for Anthrax vaccine reactions, so we ask the VA to do these things (public registries on all of these and more) when they don't we as veterans will lead. We need the diagnostic codes occurring by age group, units assigned (if possible), and what it compares to in civilian population data by age group. This would also trigger researchers in those areas to pursue potential connections whether it is exposures or potential treatment or diagnostic tests that need to be evaluated. Please consider this an identified legislative issue to be enacted by a congressional bill/law.

I include data that we obtained from within the retired/deceased VA physicians on Cancers that were occurring in the early years after Operation Desert Storm that shows 4 cancers that were occurring at an elevated rate from the normal population expected occurrences. In addition to this listing Congressman Upton had gotten a listing from the VA in the mid nineties on cancers occurring in the Gulf War veterans. This is critically important data that needs to be shared to all. Knowing that these cancers have occurred alerts the patients (our veterans) and doctors (both VA and Civilian) to do earlier screening and testing to catch cancers in the earliest stage which is needed for fast treatment to save lives!

By following through on these two efforts we might possibly identify the diagnoses that need to be included in Presumption of Service Connected for Operation Desert Storm Veterans. In addition the veterans of the Gulf War would appreciate a bill that identifies ALS, Brain Cancers, and possibly MS as Presumption of Service Connection be introduced and passed. We don't want simple VA regulations but we want laws that back those up. Therefore all VSO's, doctors, patients and their family members will know these conditions are recognized!

If needed GAO (scientists/officials) could be utilized again to collect the data and report on the above concerns on deaths (ages, cause of death) and on diagnostic codes to the Congress. The Gulf War Veterans believe that GAO reports on the whole are more balanced and complete than what we are seeing through the IOM studies. The IOM studies have proven to be almost useless and to very little benefit to the Gulf War veterans. This procedure/policy of using IOM as an arm of the VA to deny help and assistance to veterans needs to be the focus of a full Senate Investigation.

I propose a change be made for veterans, basically data that is data on diagnosed illnesses by Diagnostic code could be compared by data on the same diagnostic codes in the general population by age groups. When we experience above the normal population there should be no delays or intermediate steps to connect and compensate the veterans for those diagnostic codes and conditions. The intervening compounding factor is simply a war exposure that triggered the disease. Finally the veterans would receive the benefit of the doubt with no delay that further impacts the lives of the veteran, the quality of their lives, and the impact for the families of the veterans.

Congress needs to review the process that is occurring at the IOM in relation to Gulf War illness and exposures. This has been testified to before in front of Representative Shays Committee in Nov 2005 and no effective action has occurred. This is not what the Gulf War veterans expect of congress, to leave issues that have been identified to not be investigated and corrective action taken for over 2 years. This is simply unacceptable!

Since the last Senate Hearing during 2000 on Gulf War illness some hope of progress has been made. But hope is not enough! The VA RAC GWI was finally implemented years after the law requiring it was past. This is not acceptable and directly relates to policy of delay and denial that we have seen from all parties since 1991.

The 2004 Report of the VA RAC GWI finally slowed down the misdirecting of research money to Stress Psychological Studies of Gulf War Veterans. That took 12 years to accomplish, there are still efforts to downplay Gulf War illness as psychosomatic or stress and pushing Gulf War veterans to psychological visits away from medical internal medicine, immunology, and other clinics. This is how policy and research impacts actual care and treatment of Gulf War veterans. I believe this is due to the physicians at each VA hospital not receiving adequate knowledge of what was being done in congressional hearings or information withheld by the DoD on exposures. Training and updates of all the work that has been done is the responsibility of the VA Central Headquarters i.e. Environmental Agents i.e. Mark Brown has failed in his job. There is still a policy in place at the VA headquarters or higher that is interfering with providing what the Gulf War Veterans of Operation Desert Storm and those with reactions stemming from anthrax vaccine actually need in regards to diagnosis and treatment. Training of physicians and health care providers and sharing of all data is a central leg of our stool to reach better diagnosis and treatment of desert storm veterans in the VA health care system or in the civilian health care system. This has been and continues to be the most neglected area that affects Operation Desert Storm Veterans and potential civilian casualties that may still occur in the current War. Some one or several need to be fired! Policy from the Top down needs to be changed now not in 50 years when we are dead or when an attack occurs on civilians within the U.S. (which has happened already re WTC health effects). Truth, Responsibility, Accountability, and the best Training and Resources are what the Active Duty, Guard, and Veterans stand for and give their lives for in service to our country. It is a travesty that our Presidents, Congress, and all departments do not give that to us.

We ask that you mandate and call for a change of White House Policy, VA policy, and DoD policy now. It is will pass time that roadblock of denial and delay be completely removed publicly. The policy change will benefit our Nation and not only our veterans.

The VA research money is now being sent to the Dallas Collaborative center and this is because for years we watched the VA continue to fund research that was not focused in the right direction even after 2004. Studies that were on multiple year programs needed to be stopped but that was not done. WHY? The answer is because there was not a thread of oversight from the Congress or hearings! Money was misspent that we needed desperately to make the breaking research that would impact clinical care for us Gulf War veterans.

We are happy that the UTSW medical will now be a VA Collaborative Center. This effort is where the research for the long term effort to a potential cure will be placed. This is the long term approach but it needs input and oversight. Besides their plans to nail down the best neurological imaging/diagnostic testing more needs to be done. They must submit there plans for spending the money and other areas they will be investigating. This must be documented in a very public manner on a website with a forum for researchers and veteran patients to input their concerns and suggestions.

The other stool leg needs to be addressed re the DoD funding on Gulf War illness that disappeared in 2001 except for 5 million in FY06. The DoD Congressional Directed Medical Research Program has proven to us to be a place that can coordinate the needs of the Gulf War Illness Research. This program is the really stabilizing leg.

Through using this program Researchers that are in and out of the country that can not be funded through the VA funds due to requirement of VA employment time can become involved and help us solve the problem. An example of the problem that was faced is when Dr Paul Greengard a Nobel Peace Prize nominee in neurology was turned down for funding by the VA Research. He had stopped his busy schedule to respond to the need of Gulf War illness research. If the DoD CDMRP program had been in place then it would have been able to meet the need. The DoD CDMRP would be high gain, high risk for breaking science that relates more directly to diagnosis tailored to potential exposures that need DoD collaboration i.e. DU, anthrax vaccine, nerve agent exposure, and other hazardous exposures singularly and in combination. The treatment modalities that could be developed using the same type initiative that we use to fund weapon development from theory to rapid field use could be employed to make the rapid short term progress we need. That is why 30 million annually is needed in that area. Both to fund hypothesis developed/driven research and invited research efforts for diagnostic breaking science and treatment options. Initially I was skeptical of this program but after participating as part of the Scientific Merit Review Committee for studies that were submitted and I am now convinced that this is a workable system since it includes consumers of the illness as part of the CDMRP panels. Through this effort we can truly bring in the

best minds of this country and other countries to find answers now. As I stated earlier we have large numbers ill and DYING and for 16 years this effort was misdirected and did not serve the needs of a large group of ill combat theater veterans exposed to a hazardous environment, questionable medical practices, and a major misstep in policy when we returned ill and simply asked for the medical care we earned by serving our country. Yes there is a desperation that has been there since the start that has built over time as the quality of our lives have been affected to the point that many of our careers have been terminated, our ability to live normal day to day life has been significantly deteriorating, and too many have died.

I would like to place in the official record videotapes of the Montel Williams show "Dying to Serve" and the Discovery channel's recent program on Gulf War illness where they tested 5 veterans using a Chromosome Sky Testing that was developed and used at 3–4 medical universities (1998–2000) to show that the veterans are definitely damaged in much more severe ways than has been seen in any condition before (articles submitted as atchm). Dr Urnovitz's work in the mid 1990's showed RNA problems with the Gulf War veterans. This is the cutting edge diagnostic markers that are currently available and are not being utilized. In fact, the University that tested the 5 individuals has already experienced efforts to not make these tests available. Similar to what has occurred during the best test on DU in urine and squalene antibodies testing in individuals that received the Anthrax vaccine during Operation Desert Storm. The policy needs to be changed now. The standard that we have to reach i.e. the goal posts keeps changing because of these policies. It is time these diagnostic tools are used fully to help the Gulf War veterans seeking answers and treatment for 17 years! Interfering with scientist and doctors is an example of implementing bad policy decisions. This practice is detrimental to our very lives and to future potential civilian casualties and is against our constitutional rights and individual rights and must be stopped.

Every month we see breaking science news that could be used in Gulf War Veterans ill with Gulf War illness. I am enclosing attachments that review several of these new approaches to be considered by the DoD for invited research proposals for Gulf War illness. With every research proposal, the DoD should stress that universities should consider their cost factors that range from 40–60% and lower this factor if at all possible to encourage that more research can be done to benefit our Gulf War veterans with their assistance. The DoD officials should understand that we demand a tiger team approach including expert consultants on every research proposal in order to streamline the research in regards to time to completion and plans for clinical implementation. If we can do this for weapons development and troop protection, we should have same approach for Gulf War illness. The DoD and the VA Collaborative Research centers must involve clinicians i.e. Doctors, Nurse, Pharmacists, Lab experts, etc in the total process in order to have their inputs and also to speed the transition of research findings to clinical usage in the most timely manner. All proposals should consider ways in which more interactions and sample collection can occur from all VA hospitals. Methods making it possible for more veterans across the nation to be directly involved should be considered.

Other areas that are being neglected in research on impact of Gulf War illness are in the areas of vision changes, dental changes, viral evaluations, Cardiac implications, renal implications, and Liver implications. Some of these areas could blend clinical input from actual testing in the VA hospitals and then correlating the findings and submitting the final findings as Clinical based research.

The VA needs to ready the clinical areas to put new diagnostic tests and treatments in place. The VA needs to implement the request by the VA RAC GWI for a Clinical Advisory Committee for Gulf War illness. If the VA does not do this within 30 days after a new Secretary of the VA is in place then Congress must come forth with a bill and fast track it to a law. The integration of research findings into clinical practice at the VA has to be preplanned. The VA should be mandated by Congress to produce this plan to the Veterans Affairs Committee of the House and Senate within 60 days. Congress must respond by holding a hearing as soon as this plan is ready.

This should start with a new training and research sharing program. An excellent way to do this would be to set up teleconferencing the VA RAC GWI presentations on Research Reviews and Researcher presentations that occur at the VA RAC GWI. The VA headquarters should implement video taping of these quarterly meetings for distribution to each VA hospital and mandate the health care professional viewing as professional development and training. The plan should also address the need to set up a Gulf War Illness task force at each VA hospital to include physicians, directors, health care professionals, and Gulf War veterans. VA should update all their training documents on Gulf War Illness. VA Researchers and physicians should be offered the opportunity to attend the VA RAC GWI meetings in person. Publications

of the VA RAC GWI need to be covered in the VA Newsletters on Research and Clinical Areas. Their should be a plan to bring the Gulf War Veterans that registered through the registries to be brought back in for screenings for cancers, new diagnostic tests, and sharing of current research findings and research projects materials should be included in these sessions. These updates need to be available to Gulf War veterans being seen at the VA at each appointment. By having physicians and nurses involved in providing this information all concerned parties will be fully involved and aware of what is occurring on the research for diagnostic modalities, biomarkers, and treatment trials. The VA needs to reestablish its Gulf War Illness Specialty Centers keeping in mind they need to be geographically located in each VISN. The two War Related Centers being on the East Coast close to each other needs to be reevaluated because referrals are not happening and these centers must be strategically located across the U.S. to better serve the Gulf War Veterans with Gulf War illness.

The VA should also consider training at least one physician from each VISN in accordance with the Anti-aging board certified program and the American Environmental Training program. Both of these programs have had physicians on the civilian side of the house treating Gulf War veterans. I would be more than willing to get the VA in contact with former military doctors that are involved in these two specialty areas that have offered their expertise to assist since the early 90's.

The research proposals for treatment should also evaluate IV vitamin, COQ10, glutathione combinations that some Gulf War veterans have found as relief in dealing with their illnesses. In addition chelating treatment that has been used with nuclear plant workers need to be evaluated for use with Gulf War veterans that are testing positive for DU. Also Dr Montoya's use of Valganciclovir in Chronic fatigue patients with viral infections needs to be a treatment trial for Gulf War veterans. Many of our Gulf War veterans have never received complete blood work up studies that are available from Dr Vjordani's lab in California or Dr Berg's Hemex lab in AZ. These two labs have found treatable conditions in our Gulf War veterans that have gone to the outside civilian world to get answers. It is strange to me that Dr Vjordani's lab was recognized by the VA as outstanding but they have not utilized it in any form to get blood work done on repository samples and samples from current Gulf War Veterans seeking answers and care at the VA hospitals nationally. Dr Berg's lab did the initial sample study and paper on hypercoagulation (a treatable condition) and yet the VA has not utilized that lab or the knowledge on a treatable condition in Gulf War Veterans. This is particularly upsetting to me as a Gulf War veteran nurse because answers are out there and VA refuses to accept the answers. I am enclosing a number of medical news items that have appeared in the last 6 months that need follow up and possible invitations to be part of the researcher invited program of the CDMRP program. A great deal of research in the field of MS is available and treatment trials are there that should also include Gulf War veterans but this has not happened.

In addition there are 2 articles that I am including that need to be reviewed by Congress. One out of Los Angeles concerns stonewalling by the VA regarding cancer surveillance that is affecting the state of California collection of cancer data that could effect on the national data on Cancer. The other article concerns the millions of serum sample of Gulf War veterans at the DoD Repository and how they are running out of space and are seldom used by researchers to find answers for Gulf War veterans. Both of these items need follow up by Congress now.

I also have a large file on current research abstracts concerning Depleted Uranium that I am making available to the Congress. I include as an attachment my written testimony from a previous house hearing to cover my own personal experience as a Gulf War veteran.

Now I have covered a three legged stool in my testimony but to make that stool really solid to stand on we need the fourth leg and that is our elected leaders of this country the Congress and the executive branch of government. I have already stated the problem we have experienced due to policies of our government and lackluster effective action. Now for my final comments/suggestions to you.

I have asked the Committee staff to consider other experts to bring forward to testify. I believe the most important would be to have the preventive medical team sent into theater to finally testify to the Senate VA Committee of what happened in theater and since on Gulf War exposures. In fact I would offer a suggestion to have joint hearings of the Senate and House Veterans' Affairs Committees to cover Gulf War Exposures and Directions in Research and Clinical Implementations needed for Gulf War Illness. It is past time for this to occur! You have had General Powell and General Stormin Schwarzkopf appear years ago but the team that had the designated duty to set up medical care in theater has never been brought forward! Before we lose them to death like we lost General Boomer, General Downing, Colo-

nel Roman and others please consider this as a priority now. Their information could help all of us! They were the ones after the Gulf War that briefed the pentagon why not have them brief the Senate?

I have also mentioned to the committee other medical experts that need to testify before you so that the information on medical treatments that are available can finally have the attention through this Committee to be evaluated fully. We respectfully ask that the Senate VA Committee have more hearings to cover this issue fully. There have been too many gaps and time periods that the Gulf War Illness issue lost your attention and focus that is so needed. As I said we were sent off to the maze of IOM studies just like previous wars i.e. Agent Orange and effective action led from the Congress has been lost!

We are in a period of amazing medical research that could benefit Gulf War veterans to a better quality of life but leadership is needed from the Hill and the Executive Branch.

We can make a difference for others to follow and possibly the civilians' ill from the WTC exposures give us that opportunity and the resources needed please.

I have asked the House Veterans Affairs Committee and now I will ask you the following questions:

Will you have faith in us the veterans and those civilians as doctors and researchers and members of the VARACGWI that have committed to help to listen and hear us? Will you commit to putting the full weight of this government and its resources to this task finally? Will you listen and implement our requests? Will you follow thru with oversight on implementation? We veterans that have been in this struggle since after the Gulf War, 17 years ago, have led by ideas, suggestions, actions, and continual pleads to you our elected representatives and Senators. Please do not abandon us. Please provide us prompt and effective medical care and compensation.

Attachment 4

Chromosome testing, Sky Testing

NIH NEWS ADVISORY

NATIONAL INSTITUTES OF HEALTH, National Human Genome Research Institute

New Way Of Detecting Human Chromosome Defects Promises Better Diagnosis Of Cancer And Other Diseases

EMBARGOED FOR RELEASE
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5:00 PM Eastern Time

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Bethesda, Md—Utilizing multi-colored displays, scientists at the National Human Genome Research Institute (NHGRI) have developed a new technology for detecting defects in human chromosomes that promises to improve significantly the diagnosis of certain types of cancer and possibly other diseases as well.

In the April issue of the journal Nature Genetics, the researchers report that their novel approach, called spectral karyotyping or SKY, is far more accurate in diagnosing leukemia-associated chromosome defects than is the standard, Giemsa—or G-banding method, today's most widely used medical test for detecting chromosome aberrations.

"This new advance is a gratifying example of how the Human Genome Project, an ambitious effort to map and sequence all of the human DNA by the year 2005, is spinning off technologies with almost immediate benefit to clinical medicine," says NHGRI director, Dr. Francis Collins.

Currently, physicians use G-banding to look for abnormalities in any of a patient's 46 chromosomes—coiled strands of DNA carried in nearly every cell that contain all the genetic information necessary for the body's proper functioning. By staining chromosomes using a substance dye called Giemsa stain, laboratory specialists can produce a karyotype, or arrangement of chromosomes, that shows a distinctive banding pattern for each chromosome.

In patients with certain cancers, such as leukemia, and birth defects, such as Down syndrome, that banding pattern can reveal various types of chromosomal aberrations. Parts of chromosomes can be translocated, or swapped between one chromosome and another. Other chromosomes can be deleted or duplicated either in whole or in part.

Unfortunately, the limited staining in a G-banding karyotype does not always reveal those aberrations. Subtle translocations in chromosomes, for example, are

sometimes undetected in G-banding karyotypes, even by the keen eye of a trained specialist because the banding pattern of the "swapped" chromosome ends is identical.

SKY, on the other hand, produces brightly colored chromosomes that can clearly reveal chromosome aberrations that G-banding misses. In a study of 15 patients with different forms of leukemia, teams led by Dr. Thomas Ried at NHGRI and by Dr. Janet Rowley at the University of Chicago found chromosome aberrations in the leukemia cells that went undetected using G-banding in every case.

"Recently, cytogeneticists have used a technique called fluorescence in situ hybridization, or FISH, which enables the scientist to locate the precise position on the chromosome of one or several different DNA probes using different dyes to label each probe. SKY has the enormous advantage in that it can simultaneously uniquely identify all of the chromosomes in a single cell." says Dr. Rowley.

According to Rowley, the question then becomes, are any pieces of chromosomes in the wrong place, i.e., has there been a translocation we did not detect? Moreover, in cancer cells, there are many so called "marker" chromosomes whose size or shape is so unusual that we cannot identify them. SKY can help unravel the composition of these marker chromosomes even when they contain pieces of three or more chromosomes joined together.

SKY is a hybrid technology based on a standard genetics research tool called FISH, short for fluorescence in situ hybridization, combined with another technology called spectral analysis—a technique commonly used in astronomy to separate out the rainbow-like components of light from distant stars. SKY employs molecules called probes that attach themselves to parts of chromosomes and glow when exposed to light. The tagged portion of each chromosome appears in a specific color, creating a multi-color pattern which vividly distinguishes one chromosome from another.

Ried and his colleagues are already testing to see whether SKY can be used to detect chromosome aberrations in other diseases, such as certain birth defects. If the new technology proves successful, the researchers say, it might soon start augmenting or perhaps even replacing the current G-banding method, which is now performed some 500,000 times a year in hospitals and research centers across the United States and Canada to diagnose a wide range of diseases.

Although SKY is still a more expensive technique to carry out compared to G-banding, Ried believes that SKY's benefits outweigh its extra costs. First, because SKY provides more accurate diagnoses, doctors can better treat patients with appropriate therapies earlier and potentially avoid unnecessary and costly therapies later on. And second, because of the well-defined patterns, SKY could be assessed by computers, which would greatly speed up the diagnoses of certain diseases.

"SKY has the potential to become an important tool in molecular genetics for identifying subtle and complex chromosome aberrations without requiring any preconceived notions of the abnormalities involved," says Ried.

The NHGRI oversees the role of the National Institutes of Health (NIH) in the Human Genome Project, an international research effort to develop tools for gene discovery. The NHGRI is one of 24 institutes, centers, and divisions that make up the NIH, which is part of the U.S. Department of Health and Human Services and the Federal Government's primary agency for the support of biomedical research.

NCBI National Cancer Institute SKY/M–FISH Database SKY or M–FISH and CGH Techniquies

Spectral Karyotyping (SKY) and Multiplex Fluorescence In Situ Hybridization (M–FISH)

SKY and M–FISH are molecular cytogenetic techniques that permit the simultaneous visualization of all human (or mouse) chromosomes in different colors, considerbly facilitating karyotype analysis. Chromosome-specific probe pools (chromosome painting probes) are generated from flow-sorted chromosomes, and then amplified and fluorescently labeled by degenerate oligonucleotide-primed polymerase chain reaction. Both SKY and M–FISH use a combinatorial labeling scheme with spectrally distinguishable fluorochromes, but employ different methods for detecting and discriminating the different combinations of fluorescence after in situ hybridization.

In SKY, image acquistion is based on a combination of epifluorescence microscopy, charge-coupled device (CCD) imaging, and Fourier spectroscopy. This makes possible the measurement of the entire emission spectrum with a single exposure at all image points. In M–FISH, separate images are captured for each of the five fluorochromes using narrow bandpass microscope filters; these images are then com-

bined by dedicated software. In both techniques, unique pseudo-colors are assigned to the chromosomes based on their specific fluorochrome signatures.

The applications of SKY and M–FISH for screening genomes for chromosomal aberrations in human disease and animal models of human cancer are manifold. By making possible the unambiguous identification of even complex and hidden chromosomal abnormalities, SKY/M–FISH is particularly useful in:

- Mapping of chromosomal breakpoints
- Detection of subtle translocations
- Identification of marker chromosomes, homogeneously staining regions, and double minute chromosomes
- Characterization of complex rearrangements.

The notoriously difficult analysis of murine chromosomes has now become greatly simplified, extending the application of SKY/M–FISH to the visualization of chromosomal aberrations in mouse models of human cancer.

Visit the Ried Laboratory WebSite for SKY protocols

Selected SKY/M–FISH References

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Comparative Genomic Hybridization (CGH)

Comparative genomic hybridization (CGH) is a fluorescent molecular cytogenetic technique that identifies DNA gains, losses, and amplifications, mapping these variations to normal metaphase chromosomes. It is a powerful tool for screening chromosomal copy number changes in tumor genomes and has the advantage of analyzing entire genomes within a single experiment. It is particularly applicable to the study of tumors which do not yield sufficient metaphases for cytogenetic analysis and can be applied to fresh or frozen tissues, cell lines, and archival formalin-fixed paraffin-embedded samples.

CGH is based on quantitative two-color fluorescence in situ hybridization. Equal amounts of differentially labeled tumor genomic DNA and normal reference DNA are mixed together and hybridized under conditions of Cot-1 DNA suppression to normal metaphase spreads. The labeled probes are detected with two different fluorochromes, e.g., FITC for tumor DNA and TRITC for the normal DNA. The difference in fluorescence intensities along the chromosomes in the reference metaphase spread are a reflection of the copy number changes of corresponding sequences in the tumor DNA.

CGH has the advantage of requiring only genomic tumor DNA, making it highly useful for cancer cytogenetics, circumventing the need for high quality tumor metaphase spreads. The ability to study archival material allows retrospective analysis which can correlate chromosomal aberrations with the clinical course. Since its introduction in 1992, CGH has been applied to a broad variety of tumor types which have previously defied comprehensive cytogenetic analysis by traditional methods. CGH has, for example:

- Revealed consistent genetic imbalances and multiple amplification sites in carcinomas of the brain, colon, prostate, cervix, and breast. For instance, it identified chromosome 7 gain and chromosome 10 loss as landmark aberrations in glioblastomas, and specific gains of chromosomes 1, 8, 17, and 20 and loss of 13q and 17p in breast cancer.
- Found chromosomal aberrations in human leukemia, lymphoma, and solid tumors has identified non-random tumor and tumor-stage specific genetic changes. This information can guide positional cloning efforts.
- Become an important initial screening test for chromosomal gains and losses in solid tumor progression, and the results derived from these experiments can be applied to the development of more specific diagnostics.

Visit the Ried Laboratory WebSite for CGH protocols

Selected CGH References

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ClinicalTrials.gov
A service to the U.S. National Institutes of Health

Linking patients to medical research
Developed by the National Library of Medicine

Evaluation of Patients With Unresolved Chromosome Abnormalities

This study has been completed.

Sponsored by: National Human Genome Research Institute (NHGRI)
Information provided by: National Institutes of Health Clinical Center (CC)
ClinicalTrials.gov Identifier: NCT00001639

Purpose

The purpose of this research is to study a new way to test for chromosome abnormalities. Chromosomes are strands of DNA (the genetic material in the cell nucleus) that are made up of genes-the units of heredity. Chromosome abnormalities are usually investigated by staining the chromosomes with a dye (Giemsa stain) and examining them under a microscope. This method can detect many duplications and deletions of pieces of chromosomes and is very accurate in diagnosing certain abnormalities. It is not useful, however, for identifying very small abnormalities. This study will evaluate the accuracy of a test method using 24 different dyes for finding small chromosome abnormalities.

Children and adults with various chromosome abnormalities may be eligible for this study, including, for example, people with developmental delay or mental retardation, abnormal growth features or growth retardation, and certain behavioral disorders. Participants will be evaluated in the clinic over a 1- to 3-day period, depending on their symptoms. All participants will be examined by a genetics specialist and will have a physical examination and possibly X-rays, computerized tomography (CT) scans, magnetic resonance imaging (MRI), ultrasound studies and medical pho-

tography. Blood will be drawn for chromosome testing-about 3 tablespoons from adults and 1 to 3 teaspoons from children.

When the test results are available, participants will return to the clinic for follow-up evaluation and review of the test findings. The genetic and medical evaluations, along with their implications, will be discussed.

Condition

Abnormalities
Failure to Thrive
Mental Retardation
Microcephaly
MedlinePlus related topics: Birth Defects; Developmental Disabilities;
Facial Injuries and Disorders; Growth Disorders; Head and Brain Malformations
Genetics Home Reference related topics: Developmental Disabilities
Study Type: Observational
Study Design: Natural History
Official Title: Evaluation of Patients With Unresolved Chromosome Aberrations
Further study details as provided by National Institutes of Health Clinical Center (CC): Total Enrollment: 263
Study start: December 1996; Study completion: October 2000

There is a range of genomic aberrations from aneuploidy down to single base pair deletions or inserts. Present technology uses microscopic cytogenetics for detection of large rearrangements (greater than 2 Mb) and molecular techniques for small rearrangements (less than 2 Mb). There is a gap in practical diagnostic technology in that microscopic cytogenetics has poor sensitivity for aberrations less than 5 Mb and the molecular techniques are cumbersome for clinical use in the megabase range. In many cases it is possible to determine that an aberration is present by microscopic cytogenetics but cannot be characterized. We propose to use Spectral Karyotyping (SKY) and supplementary FISH and molecular techniques to characterize these aberrations. Subjects will be seen in OP9 for a clinical genetics evaluation and phlebotomy for SKY. Confirmation of SKY results will be performed by standard FISH, genomic content mapping, and other standard techniques.

Eligibility

Genders Eligible for Study: Both Criteria
Physical anomalies or developmental anomalies.
Karyotype showing derivative chromosome abnormality that is not fully characterized.
No abnormal parental karyotype.
No prenatal specimens.
Probands of all ages, genders, and ethnic origin are eligible.

The proband must have a non-mosaic abnormal G-banded chromosome analysis of good quality that shows one or more derivative chromosomes whose foreign component cannot be determined by standard G-banding techniques.

The parents should also have G-banded chromosome analysis prior to eligibility for consent 2. If this has not been done by the referring physician, it may be done as part of the protocol.

The proband with the abnormal karyotype should have one or more of the following features: dysmorphic features; developmental delay or mental retardation; growth retardation, microephaly, short stature or failure to thrive; behavioral disorder

Biological parents must be willing to supply a blood specimen. If they have any of the features listed above, they must attend the clinic if the proband is to be eligible.

The proband must be evaluated by the NCHGR clinical genetics service by the PI, a co-investigator, or his associates.

Mothers will be queried about potential non-paternity. If non-paternity is possible, the family will need to undergo clinical paternity evaluation before they are enrolled in the study.

Location Information

United States, Maryland

National Human Genome Research Institute (NHGRI), Bethesda, Maryland, 20892, United States

More Information

Study ID Numbers: 970045; 97–HG–0045
Last Updated: July 10, 2006
Record first received: November 3, 1999
ClinicalTrials.gov Identifier: NCT00001639
Health Authority: Unspecified
ClinicalTrials.gov processed this record on October 03, 2007

University of Pittsburgh Cancer Institute

A National Cancer Institute (NCI)-designated Comprehensive Cancer Center

UNIVERSITY OF PITTSBURGH RESEARCHERS USE "FISH" AND "SKY" TO STUDY CHROMOSOMES

PITTSBURGH, Nov 17, 1997—Using two state-of-the-art technologies, scientists at the University of Pittsburgh's Department of Human Genetics are lighting up human chromosomes in a colorful display to easily locate errors that give rise to disease. These technologies are FISH (Fluorescence In Situ Hybridization) and SKY (Spectral Karyotyping).

Each person has 23 pairs of chromosomes, large coils of genetic material. Pitt researchers are probing human chromosomes with FISH and SKY to reveal the tapestry of genes that instruct the body to develop and function properly and to yield information that could help biomedical researchers develop sensitive tests to detect disease and possibly aid in choosing the best treatments for specific disorders. "With our new FISH and SKY instruments, we can visualize specific genes or chromosomal regions to identify the defects at a fundamental level in a variety of disorders, such as what chromosomal changes are associated with the development and progression of a variety of cancers," said Susanne Gollin, PhD, associate professor of human genetics at the University of Pittsburgh, where she is the director of the Cytogenetics Laboratory.

"Already, these technologies are allowing us to detect chromosomal alterations in otherwise normal looking cells lining the mouth of patients with oral cancer. These alterations identify cells that may grow into new cancers. Using such information, we may be able to screen individuals at risk for oral cancer, as well as develop and apply much better prevention and treatment strategies," noted Dr. Gollin, who also directs the University of Pittsburgh Cancer Institute's Cytogenetics Facility. Pitt's cytogenetics capabilities are unique in the region. SKY is not available elsewhere in the tri-state region, including Pennsylvania, Ohio, and West Virginia, according to its manufacturer, Applied Spectral Imaging of Carlsbad, CA. Aside from detecting the most subtle chromosomal flaws underlying disease, FISH and SKY can be used to learn whether a chromosome has received a new gene delivered as part of a gene therapy; track the integration of foreign, disease-causing viruses into chromosomes; and assess how anti-cancer drugs alter chromosomes before they kill tumor cells. Not only are these technologies more informative when studying abnormal cells than standard ways of examining chromosomes (called karyotyping), they are also quicker because they combine powerful visualization capabilities with rapid, computerized analysis, according to Dr. Gollin.

With FISH technology, researchers expose a cell's chromosomes to fluorescent probes made of normal human DNA segments. These probes bind (hybridize) tightly to a specific region of a cell's genetic material. Investigators use FISH to count the number of chromosomes and/or copies of a particular gene in a cell and to identify unusual regions that are amplified, or present in extra copies. Too few or too many chromosomes or gene copies indicate a serious genetic defect in that cell. Using a different form of FISH, called comparative genomic hybridization, investigators can identify chromosomal regions that are gained or lost in abnormal cells, including tumor cells. For instance, researchers can expose human cells to a probe made of normal DNA (labeled red) and a probe made of tumor DNA (labeled green). This technique enables scientists to learn whether chromosomes have lost a section of DNA containing a normal gene that suppresses cancer growth (hence the absence of any green) or gained too many copies of a DNA section containing a normal gene that drives a cancer's growth (extra green).

SKY technology, yet another form of FISH, is used to study more complex changes in genetic material because some of the probes it employs are labeled with not one but several colors. These multicolored probes bind to the chromosomes. This new portrait's panoply of colors, many of which are similar, cannot be differentiated by the human eye, but SKY's spectral imaging hardware and computer software can discriminate even the finest variations in the wavelengths of color (spectra) emitted

by each dye or combinations of dyes marking a chromosome. After the SKY instrumentation processes this information, the result is a vivid display. Using SKY, researchers can plainly see the chromosome rearrangements in a cell. Normal chromosomes are each one color. Abnormal chromosomes may be composed of two or more different colors, signifying their origination by mixing and matching of two or more different chromosomes. Recently, Pitt became the first test site in the United States for software-driven remote access to classical and molecular cytogenetic results. CytoNet software and the CytoVision System are produced by Applied Imaging, headquartered in Santa Clara, Cal., with its North American sales office located in Pittsburgh.

"The CytoNet provides novel communications capability," said Dr. Gollin. "The CytoNet is envisioned to serve two currently unmet needs: viewing of clinical cytogenetics results by cytogeneticist consultants or laboratory directors who are offsite to obtain professional input or second opinions; and viewing of research results and discussion between an investigator and the director of a specialized cytogenetics core laboratory, such as the UPCI Cytogenetics Facility. Not all institutions have cytogeneticists or cytogenetics laboratories for research applications. This software facilitates use of these shared resources by investigators at other institutions." The Cytogenetics Facility is funded by the UPCI's cancer center support grant from the National Cancer Institute. Funding for the SKY and CytoVision instrumentation was provided by the National Center for Research Resources, National Institutes of Health. For additional information about the UPMC Health System or the University of Pittsburgh Cancer Institute, please access the web links.

UPMC News Bureau

Attachment 5: Point paper Highlight of Actions needed

POINT PAPER SUMMARY OF TESTIMONY
ACTION PAPER FOR ADDRESSING ISSUE OF GULF WAR ILLNESSES

1. The last benefits law(2000) for Gulf War illness had within the original bill not only Chronic Fatigue Syndrome and Fibromylagia but also Neurological Autoimmune Diseases/Disorders. Unfortunately the Neurological Autoimmune diseases/disorders was removed and now in 2007 we are asking that wording to be added. We are asking for a bill to be moved quickly that adds Brain Cancers, ALS, and MS to the presumption of service connection for Gulf War Veterans. The Brain Cancers and ALS should have no problem since the VA has agreed by regulation. We need a bill that is fast tracked to be completed this session of congress. We want this done by Law not by VA discretionary action.
2. In regards to legislation in the authorization and appropriations area, the congress and senate should follow the Lead of the VA Research Advisory Committee on Gulf War Illness and Gulf War Veteran's Organizations. Just yesterday the House Appropriations Committee did not do that and has in effect caused potential detrimental action in the needs of the Gulf War veterans community.
3. VA attitude starts at the top and goes down. The hearing today will show the detrimental effect that attitude has caused for 16 years. That attitude has to be turned on its head. People within the VA system have directly affected tens of thousands no hundreds of thousands Gulf War Veterans in regards to the VA Benefits, VA Health Care, and VA Research. It is time now that certain people be removed from their positions for their deliberate misguidance, mismanagement, and ill regard to Gulf War veterans needs.
4. All VA Directives/Policies/Guidance/Contracts must be faced with a Stop Order and Investigated. They have led to a Direct Breech of Duty to the Gulf War Veterans.
5. New Directives/Policies/Guidance/contracts must be submitted and reviewed by the VA RAC GWI and other congressional Committees before they are officially released.
6. Dental and Eye Exams must be Mandated for ODS Veterans now. Data that must be gathered and shared with the VA RAC GWI and House and Senate VA Committees and government Reform Committee. Treatment for Dental and Eye conditions should be allowed through the VA for these veterans regardless of VA rating.
7. VA Outreach and all forms of Communication to ODS Veterans must be started in a robust manner expeditiously. This should include the newest research

information and exhibit a new VA attitude a true we are here to serve the veteran.

8. VA physicians and medical personnel must be notified to perform expansive lab work measurements to cover:
   A. Immune System Function
   B. Viral Panels
   C. Hypercoagulation Lab work
   D. Thyroid system functions
   E. Adrenal Gland Function
   F. Pituitary Gland Function
   G. Hormonal function
   H. Renal Function
   I. Cardiac Function
   J. Liver Function
   K. Screening Cancer workup labs
9. Data gathered from lab work needs to be collected and analyzed and sent to the Research Advisory Committee and reports on same should be issued on the VA Website so that physicians, researchers, and patients alike have the information.
10. Treatment of any abnormalities should be started as soon as results are obtained.
11. Data on all causes of deaths should be assembled and posted as Data Report from the VA on its website.
12. Data on all Diagnosed illnesses for ODS Veterans must be collected and also published on the VA Website.
13. Two additional advisory Committees similar to the VA RAC GWI in the areas of Clinical Care and Benefits should be legislated and should be implemented ASAP.
14. New Clinics should be initiated at each VA Hospital specifically for Operation Desert Storm Veterans. The staff should be dedicated and then thoroughly brought up to current state of knowledge on relevant physiological based research that has occurred. Then the educational process for Medical staff and medical personnel should be expanded rapidly.

    The educational process should involve routine scheduled teleconferences and videotape reviews. The Videotaping of Jim Binns, Lea Steele, Beatrice Golumb, Dr Roberta Hailey, and Dr Roberta White should be produced and distributed ASAP. New tapes with other leading researchers and clinicians should follow.
15. The registry program and environmental agent program should be renewed and expanded. The individuals that went thru these registries should be brought back in for updating of medical progress, expanded lab work, and any other diagnostics.
16. A proactive aggressive Cancers and Neuro Auto Immune Diseases/Disorders Screening Program for Operation Desert Storm Veterans should be legislated and implemented ASAP.
17. A directive should be sent out to all VA hospitals that symptoms suggestive of ALS or MS need to have through and complete diagnostic workups done regardless of VA Rating.
18. Anti Aging Board Certified Physicians and Environmental physicians should be proactively recruited for contracts with the VA headquarters and VA hospitals to provide consultation and physician education programs immediately.
19. DOD AND ACTIVE MILITARY SERVICE MEDICAL PROFESSIONALS NEED UPDATE TRAINING ON ASSESSMENT OF ENVIRONMENTAL EXPOSURES AND REVIEW OF CURRENT RESEARCH.
20. New DoD and Service Components guidance and regulations on all environmental exposures need to be initiated. Documentation of potential exposures and tracking for active duty needs to be reviewed. Any and all potential health affects need to be documented.
21. DoD must review and update exposure lists to include AF, Navy, and Marine units and notify the individuals affected.
22. Assurance needs to be in place by oversight that DoD Military services are recording all vaccines appropriately with lot numbers.
23. Individuals listed in Exposed areas must be notified by DoD and VA by letter of the increase risk of Brain Cancers/ALS.

Attachment 6

Ms. Julie Wilson, United States Department of Veterans Affairs, Illiana VA Medical Center, Danville, Illinois. and to The United States Department of Veterans Affairs, The Inspector General, Washington, D.C.

The latest nonsense comes from the American Legion. I have confirmed that the American Legion sent this out with Mr. Bill Johnson (317–630–1239) from the American Legion National Headquarters in Indianapolis, Indiana. Please let all Indiana VA staff and all VA National staff and VA facilities staff members nationwide know what was done and that the Legion has absolutely no authority to suspend or tell veterans that our benefits have lapsed and then to demand payment of $20 in check or credit card for reinstatement of benefits.

I REQUEST FORMAL IMMEDIATE WRITTEN CONFIRMATION FROM THE DIRECTOR OF THE ILLIANA VA MEDICAL CENTER AND FROM THE UNITED STATES OF AMERICA DEPARTMENT OF VETERANS AFFAIRS SECRETARY appointed by the President of the United States that my benefits have not lapsed as stated by Mr. Robert Spanogole, National Adjutant, The American Legion, in the SIGNED letter THAT I received from the HIM AND THE American Legion on October 2, 2007. ALTHOUGH MR, JOHNSON OF THE AMERICAN LEGION TOLD ME THIS WAS A ERROR NEEDLESS TO EXPLAIN I DO NOT TRUST ANYONE.

The specific—relevant information follows:

I received a letter on October 2, 2007 from Robert Spanogle, National Adjutant, American Legion, National Headquarters, P.O. Box 7017, Indianapolis, Indiana that quote: "This letter is to inform you that benefits you are entitled to as a Veteran of the United States Armed Forces have lapsed.

Through a special reinstatement program, you are being given this opportunity to reinstate these important benefits, for which you remain eligible in accordance with the enclosed publication 57 "Veterans Guide to additional Benefits.

To reinstate your benefits you need only return the enclosed Reinstatement Form according to the instructions printed on the form. Please note the reinstatement period designated for your last name at the top of the page of this notice. The absolute deadline is 3 pm on the last date shown above.

(from top of the form), Deadline: November 5, 2007, 3:00 pm ET

Reinstatement period for veterans with last names beginning R–S September 24–November 5, 2007 3:00 PM ET" end quote

The implication is that I must renew my membership in American Legion Post 71; Urbana, Illinois by November 5, 2007 at 3pm ET by sending them a check for $20 made payable to "The American Legion" to reinstate my VETERANS benefits.

I have TWICE called the American Legion National commander Marty Conaster, Champaign, Illinois 217–359–4211 and asked him to call me immediately,. NO RESPONSE! I called the Urbana Post 71 at 367–3121. The Urbana American Legion Post 71 officer I spoke to did not know this was sent out on their behalf. He agreed this was wrong! He called me back today with an apology.

THIS IS ABSOLUTE NONSENSE AND PURE INTIMIDATION TO OBTAIN $20 FROM ME.

I must ask if any Federal laws were broken if so what must be done?

I BELIEVE that Mr. Spanogles's treatment of me as a retired and 60% disabled veteran who fights for medical care for all of our veterans and myself is simply unacceptable and deserves a Department of Veterans Affairs censure for scaring not only me and my wife but thousands of others who probably received this same letter. We did not sleep well last night and today has been a roller coaster.

MR. SPANOGOLE'S TREATMENT OF OBVIOUSLY THOUSANDS OF VETERANS WHO ARE SEEKING HELP AND WHO RECEIVED THIS SAME LETTER IS A TRAVESTY.

I suspect that I am only one of many who received this letter.

I believe that I and all others who received this letter deserve a nationwide public apology for this action.

At the bottom of the letter:

quote: "Important; There is no mandate to extend the deadline shown or to offer additional periods of reinstatement. do not delay in returning your reinstatement form." end quote

I have absolutely confirmed that the American Legion sent the letter. It is directly from the American Legion National headquarters.

The suspect that this organization is just trying to scare me—us into sending them $20 for membership. The membership demand in my case is renewal of my membership in American Legion Post 71 in Urbana. I belong did belong to this Post but have not renewed my membership because they simply refuse to help us when we needed and asked for help.

The envelope has return address of: "The American Legion National Headquarters, Department of Veteran Notification, National Adjutant, P. O. Box 7017 Indianapolis, In. 46207–7017"

The envelope has the huge letters "Deadline Notice for Veterans of the United States Armed Forces to Reinstate Benefits"

the enclosed return envelope has the address: Benefit Reinstatement, c/o the American Legion National Headquarters, P.O. Box 7017, Indianapolis, In 46207–7017

The letter says I can reinstate my benefits by visiting www.members.legion.org

It gave me a temporary membership number of 2022422818. The direct telephone number of the American Legion National Headquarters in Indianapolis, in. is 317–630–1200.

Thank you,

Major Doug Rokke, Ph.D.
U.S. Army, retired

Attachment 7

This is a brief of my experiences. My name is Brent Casey, a Gulf War veteran, served as a medic with the 82nd Airborne in 90–91. Sept 05' I received a letter from the DoD which was a unit list released by the Pentagon. These units were exposed in and around the Kamisiyah demolition pit in Spring 91' and my unit (3rd/73rd Armor) was on this list.

Scared to death and already suffering terribly from what I now know is fibromyalgia, and never having been to a VA hospital in my life, my family convinced me to go see a VA doctor for a check-up. My first visit resulted in medication for hypertension, and 19 19 flagged on a PTSD checklist, and obviously a diagnosis. After 6–8 months of PTSD counseling (keep in mind I had never heard of PTSD), groups and one-on-one, I discovered a Gulf War exam offered at the hospital and I signed myself up for the exam.

By Sept. 06' I was diagnosed with fibromyalgia, depression, chronic rhinitis, paresthesias, erectile dysfunction, fatigue, hypertension and after 2 sleep studies, sleep apnea. In Oct. 06' in my own research, I discovered a PTSD Residential Rehabilitation Program in Lexington, KY (42-day), I completed the program in Dec. 06'. While in Lexington, again through my own research, I discovered the WRIISC in New Jersey and started working on a referral from a primary care physician.

I was accepted into WRIISC for a 2-day very intense work-up and history including, exposure assessment, social work evaluation, psychological assessment, neuropsychological assessment, and complete physical, all with special attention to deployment related concerns of mine. Overall recommendations that I just received from WRIISC include but are not limited to: Mr. Casey meets the criteria for the unexplained condition of Chronic Fatigue Syndrome, and Mr. Casey meets the criteria for Irritable Bowel Syndrome. I was also tested for DU (24-hr. urine) only after my own research and request, it was tested in Baltimore in Nov. 06' and supposedly the results are normal and I will not have any adverse consequences.

Anyhow, it is now exactly 2 years later—and to say the least I am still blown away—but I do have a few answers to some of my questions. I have an agent who is helping me with my claim, but I'm still not sure if I am coming or going. I had 5–6 Dr. appt. last month and have about that many so far to keep up with in Oct. (Mental health, Rheumatology, PTSD Groups, Primary care and labs an EENT referral, and Physical medicine specialist referral, and an ophthalmology referral, so my healthcare is a full-time job. I have had a MRI, CT-scan, EMG, Sperm/fertility test, C–PAP machine nightly, CXR, and numerous blood tests of coarse. I hope this is appropriate information for your compilation and I would love to help any way that I can. Feel free to call me to discuss anything that will help you.

Sincerely,

Brent Casey

Attachment 8

I am increasingly frustrated. . . . I am asking veterans of Desert Storm to write and tell us of your discoveries that could help others re diagnosis findings . . . what was found, who tested, how others can get the same. . . .

Treatment . . . what have you found? Who got you there? Where can other vets get it?

And most of all

How is your quality of life . . . what have you managed to do re education, work, family HORRIBLE! Everyone is SICK!

How are your spouses and children? What has been found on their medical condition that could help other veterans? My only child (M–31,has degenerative joint disease and its eating away at him, he has high b/p, and his teeth are just wearing away, they aren't rotting??? Just crumbling?? My wife same thing with her teeth, and she hurts all the time and again, they just try and pass it off as diabetic, and its FREAKING NOT!

How has your testing and treatment been at the VA? NO, I have been blown off by them for yrs. said it was all in my head! (yah it is I have seizures).

Have you found civilian help? Where and who should veterans contact . . . which doctors? HAH your joking right! NO ONE WANTS TO HELP US, we are just waiting to die.

How many are having significant dental problems? YES! root canals, and got tired of that rout and just having them pulled out now.

How many have had hearing tests that show ototoxicity? NO TEST, but my hearing isn't great anymore and my ears hurt a lot. and they just say old age *54 yr old.

How many are experiencing increasing vision problems? Yes and had surgeon to correct it, and now find I have cataract forming anyway.

Are you having thyroid, hormone problems, cardiac, renal conditions? Are they being tested for? By who? Are you being treated for these? Again, never tested for anything and just tired of being blown off and told its all our own fault for, thinking we feel ill.

Like I said, we are just waiting to die, figure its got to be better than the hell we are living in now.

Tom Daggett 10 yrs U.S. Army 54 and also FED UP

Committee on Veterans' Affairs
Subcommittee on Health
August 2, 2007

Meryl Nass, M.D.
Mount Desert Island Hospital
Box 8
Bar Harbor, ME 04609

Dear Meryl:

In reference to our Subcommittee on Health hearing on "Gulf War Exposures" held on July 26, 2007, I would appreciate it if you could answer the enclosed hearing questions by the close of business on October 2, 2007.

In an effort to reduce printing costs, the Committee on Veterans' Affairs, in cooperation with the Joint Committee on Printing, is implementing some formatting changes for materials for all full and Subcommittee hearings. Therefore, we would appreciate it if you would provide your answers consecutively and single-spaced. In addition, please restate the question in its entirety before the answer.

Please provide your response to Cathy Wiblemo at the Committee. If you have any questions, please call 202–225–9154.

Sincerely,

MICHAEL H. MICHAUD
Chairman

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1. ***Gulf War Illnesses***—Everyone on this panel agrees that Gulf War Illnesses are real and that more should be done by way of research, outreach and treatment.

- *In your professional estimation, what is the biggest challenge facing VA today with regard to Gulf War Illnesses?*

For at least 10 years, the personnel in place to implement Gulf War Illness programs have prevented good research, good diagnostics and good treatments for Gulf War veterans. A group of individuals at VA have had control over research, outreach and treatment, and these officials have ensured that the focus of both research and treatment has been primarily psychological. The medical evaluation strategies adopted by the VA have specified that investigations of veterans' symp-

toms be limited, and the recommended treatment strategies have primarily used psychiatric drugs. However, I must assume that these individuals have carried out VA policy, since there is no evidence they were instructed to do otherwise. Unless and until VA policy aligns with the goal of doing our best for GW veterans, things cannot change.

A true story: in 1999, a Committee on government Reform staffer told me that the reason Gulf War veterans were being diagnosed and treated for psychiatric illnesses was because disability pensions could be limited to 2 years more easily than if they were acknowledged to have physical illness. I cannot confirm if this is true, but it may be relevant to the question of why VA made the choices it did regarding GW research and patient care. Recent revelations about the use of "personality disorder" diagnoses [1] by the Army to discharge veterans without a medical board or pension suggest that these choices have been deliberate.

- *What would your recommendations be to VA to ensure that what has happened to the Gulf War veterans does not happen to the newest generation of veterans returning from OEF/OIF?*

At the Senate Veterans Affairs Committee hearing where I testified on Sept. 25, 2007, DoD's representative, Michael Kilpatrick, M.D., stated in answer to a question that "15–20% of those who've fought in Iraq recently are returning with "'ill-defined' medical symptoms, Kilpatrick said." (McClatchey-Tribune, Sept 26) Later Kilpatrick told a reporter he did not mean to imply they all had GWS.

It should be a concern to all of us that DoD has already identified a developing medical problem in a significant number of returning soldiers.

In order to provide optimal care to OIF and OEF veterans, VA needs to know the types and severity of medical conditions these veterans face, and their frequency. An accurate needs assessment cannot be made without reliable information from DoD to VA. Media reports suggest VA relies on information from military medical boards, but note that many veterans whose status should prompt a medical board are not going through the board process. How has this affected VA planning?

Therefore, since information supplied by DoD on the health of troops has not always been accurate and complete, VA should be performing its own surveillance of new veterans, in order to best predict the medical needs of returning soldiers.

New entrants to the VA system should complete a detailed questionnaire and evaluation by practitioners who are knowledgeable about the physical and psychological needs of veterans returning from combat. Creating a database from these assessments could help to prepare further investigations and treatments for returning troops, and identify those who have developed chronic medical conditions for specialized care.

Congressional oversight should address VA's programs for dealing with the 15–20% of troops with ill-defined conditions identified by Dr. Kilpatrick, as these veterans are most at risk of slipping through the cracks in the way that happened to veterans with Gulf War Illnesses.

2. ***DoD/VA—***Getting accurate, up-to-date information on pre-deployment and post-deployment health records, where service members were located and other pertinent information from DoD, has, in the past, been characterized as difficult.

- *Do you believe that this exchange of information between VA and DoD has improved with current deployments to Afghanistan and Iraq?*

Regarding whether things have improved, I can only refer to the GAO report of September 26, 2007: [2,3] DoD and VA: Preliminary Observations on Efforts to Improve Health Care and Disability Evaluations for Returning Servicemembers. See pages 19–22.

http://www.gao.gov/new.items/d071256t.pdf

Clearly, information exchange is not where it should be.

My experience has been that DOD jealously guards information on the health of troops. Spokespersons have not always reported accurately to media on this issue,

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[1] http://www.thenation.com/doc/20071015/kors Joshua Kors. Specialist Town Takes His Case to Washington. The Nation. September 27, 2007.

[2] http://www.gao.gov/new.items/d071256t.pdf DOD and VA: Preliminary Observations on Efforts to Improve Health Care and Disability Evaluations for Returning Servicemembers. GAO–07–1256T, September 26, 2007. Pages 19–22 cover the data sharing issue.

[3] Hope Yen. GAO Again Slams VA and DoD for Failing to Care for Wounded Iraq War Veterans. AP/Army Times September 27, 2007. "The report said the Pentagon and VA still remain far away from having a comprehensive system for sharing medical records as injured veterans move from facility to facility."

and military medical studies are frequently at odds with independent research on the health of troops. The Congressionally mandated Defense Medical Surveillance System database is being maintained, but the data are not shared with independent researchers, despite Federal advisory Committee recommendations. The data are only 80–90% accurate, according to GAO, CDC and the Navy Environmental Health Center in San Diego. Presumably, more effort could be made to improve the accuracy of the database. Congress could require that data be shared.

Unpublished studies of the database are not shared either. Accompanying this response, I have included two lists, obtained via Freedom of Information Act requests, of titles of informal studies performed by the Army Medical Surveillance Activity, which used this database for the studies. I have so far been unable to obtain any of the actual studies from the Army (using FOIA). Many of these studies, especially those on GWS and on anthrax vaccine, should be of interest to the Congress and the VA.

[One list appears at the end of these responses and the other list is being retained in the Committee files.]

- *In your professional opinion, would you say the lack of information exchange or delayed exchange was a primary factor in hindering research efforts regarding Gulf War Illnesses?*

Yes. Procedures for investigating and dealing with toxic exposures could have been initiated, appropriate infections sought, etc., had VA been aware of the types of exposures that had been experienced by individual veterans when they first arrived in the VA system. The lack of good information from DOD made it very difficult to study most of the Gulf War exposures, since without accurate information it was uncertain who was exposed to what, and the magnitude of the exposures. The problem is only partly one of information exchange; it is uncertain whether DOD monitored and recorded noxious exposures to which its soldiers were exposed. This includes exposures to sarin, to unvented tent heaters, to vaccines, pyridostigmine bromide (PB) and depleted uranium. Thus the later research had to rely on so-called "self-reports" of exposures—but the research was also criticized for using these unvalidated reports.

However, the main factor that hindered good Gulf War illness research after the immediate post-war period was the lack of will to do so, shared by VA and DOD.

3. ***ALS***—Mr. Mikolajcik proposed in his testimony that a congressionally directed ALS Task Force should be established to help provide direction in ALS research and to develop a strategic plan to tackle this illness. The 30- 60- 90-day timeline he suggested in his testimony lays out some structural parameters.

- What are your thoughts on creating another task force or entity to look into ALS?

A task force is a good way to review the problem and recommend directions to pursue. However, the value of a task force is totally dependent on its chairman, members and staff. It also needs to be given unfettered access to data, and the power to have its recommendations carried out in a meaningful way.

For example, exposure to electromagnetic fields has been linked to ALS in a number of studies.[4] In order to pursue this link most productively, information on the electromagnetic fields generated by DOD weapons, communications systems and other equipment would need to be known, and the exposures in different groups of soldiers identified. It is unlikely that DOD would cooperate in providing these data.

In order to avoid reinventing the wheel, it should be noted that in 2001, a UK (government) expert panel made some research recommendations about ALS and electromagnetic fields:[5]

"Case-control studies are, however, appropriate for investigating the aetiology of amyoptrophic lateral sclerosis and, in view of the rarity of the disease, are generally preferred to cohort studies. A large-scale case-control study might, therefore, be profitably undertaken in which special enquiries were made about:

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[4] Christoffer Johansen and Jorgen H. Olsen. Mortality from Amyotrophic Lateral Sclerosis, Other Chronic Disorders, and Electric Shocks among Utility Workers. American Journal of Epidemiology Vol. 148, No. 4: 362–368. "The excess mortality from amyotrophic lateral sclerosis seems to be associated with above-average levels of exposure to electromagnetic fields and may be due to repeated episodes with electric shocks." http://aje.oxfordjournals.org/cgi/content/abstract/148/4/362

[5] ELF Electromagnetic fields and neurodegenerative disease. Report of an advisory group on non-ionising radiation. National Radiological Protection Board, 2001. 12(4).http://www.hpa.org.uk/radiation/publications/documents_of_nrpb/pdfs/doc_12_4.pdf

1. employment in electrical occupations, with special reference to the occurrence of severe electric shocks.
2. medical treatment with electroconvulsive therapy that could be confirmed from hospital records.
3. exposure to transcranial magnetic stimulation (Walsh and Cowey, 1998), a technique for magnetic induction of neuronal activity in small brain volumes, which is used both experimentally and clinically.

More work is needed to explore the effects of electromagnetic fields on neurons and glial cells. In particular, the effects of both brief explicit shock and prolonged exposure to electromagnetic fields on intracellular Ca2+, superoxide dismutase (SOD) activity and enzyme function in neurons deserve particular attention."

- *Do you believe that the direction VA is taking with ALS is the right way?*

I cannot comment. ALS has been one disease that has been associated with 1991 Gulf War service. We do not know how many more diseases may also be associated, as the (relatively simple) epidemiological research to study this has not been done by VA and DOD.

4. ***Where Do We Go From Here*—**Sixteen years have passed and veterans of the Gulf War are still fighting to be recognized and not forgotten.

- What would your recommendations be on how to effectively move forward with Gulf War Illnesses research, outreach, education and treatment?

As I was preparing my responses to these questions, the Senate Veterans Affairs Committee asked me to provide testimony on Gulf War Illnesses. My response is included in that document, which I am attaching.

[The Senate Committee on Veteran's Affairs testimony appears at the end of this document.]

Accountability for program success is crucial to the effort, and Congress should demand regular reports on the Gulf War Illness program.

5. ***Gulf War Syndrome*—**Dr. Nass, you acknowledged that symptoms of Gulf War Syndrome are not unique and that they overlap closely with other diseases, conditions and syndromes.

- Can you please describe the health effects of a typical case of Gulf War Syndrome?
- How do you treat a patient suffering from Gulf War Syndrome?

[The response to these questions are contained in the Senate Committee on Veteran's Affairs testimony, which appears at the end of this document.]

6. ***Research*—**Dr. Nass, you said that the research to determine the extent of which the anthrax vaccine may have contributed to Gulf War Illnesses has simply not been done.

- *Based on my practices and studies, do I believe there is a connection (between anthrax vaccine and Gulf War Illnesses)?*

There is no doubt about their connection, which has been identified in at least 6 different studies. What I was trying (clumsily) to say in my testimony was that the magnitude of the anthrax vaccine contribution to Gulf War Illnesses was not known. In other words, we do not know what percentage of cases might be due to anthrax vaccine alone, though we do know the vaccine alone has caused an illness identical to GWS in non-deployed soldiers. (Even the FDA-approved label for anthrax vaccine lists GWS, as defined by CDC, as a reported adverse reaction.) In my opinion, anthrax vaccine added to the burden of toxic exposures faced by soldiers in the Gulf and increased the number of soldiers who developed chronic illnesses. Many soldiers who never received anthrax vaccine became ill, but receiving the vaccine almost certainly increased one's risk of developing GWS.

Meryl Nass, M.D.
September 30, 2007

LISTS OF TITLES OF INFORMAL STUDIES PERFORMED BY THE ARMY MEDICAL SURVEILLANCE ACTIVITY

21JAN05 BURDEN OF HIV, HEP C, COLORECTAL CA DISEASE IN ALL BENEFICIARIES/MTF ONLY (TRICARE MGT ACTIVITY)

6DEC99 BOSNIA AND SWA ANTHRAX VACCINATIONS (OSD) 20DEC99 ANTHRAX IMMUNIZATIONS FOLLOW–UP (OTSG)
4JAN00 SERUM FROM SWA VETS (AFMOA)
5JAN00 ANTHRAX VACCINE AND THYROID DISEASE (AFMOA)
5JAN00 ANTHRAX VACCINE AND GUILLAIN BARRE SYNDROME (AFMOA)
15FEB00 POTENTIAL ANTHRAX OUTCOMES (OTSG)
1MAR00 ANTHRAX VACCINATIONS BY LOCATION (CDC)
3MAR00 ACUTE LEUKEMIA AND ANTHRAX VACCINE OTSG TIMING NOTICED LEUK PROB AFTER AVA INITD
16MAR2000 POSSIBLE ANTHRAX IMMUNIZATION–RELATED NEOPLASMS
24MAY00 CRUDE RATES OF AMBULATORY VISITS BY ANTHRAX STATUS (AFMOA)
31MAY00 POSSIBLE RISK FACTORS FOR REPORTING ADVERSE REACTIONS TO ANTHRAX VACCINE (OTSG)
1JUN00 PREGNANCY OUTCOMES FOLLOWING ANTHRAX VACCINATION (OTSG)
13JUN00 SUMMARY OF OTHER VACCINES RECEIVED THE SAME DAY AS ANTHRAX (ANTHRAX VACCINE PROGRAM)
14JUN00 SAME DAY IMMUNIZATIONS (AMSA)
21JUN00 PREGNANCY OUTCOMES RELATIVE TO ANTHRAX VACCINATION (AMSA)
6SEP00 ANTHRAX RISK FACTORS PART 2 (OTSG)
16OCT00 BREAST CANCER AND ANTHRAX VACCINATIONS (OTSG)
6NOV00 ANALYSIS OF SIDR–EIDS DATABASE (AMSA)
6NOV00 INCIDENCE ANALYSIS OF ANTHRAX VACCINE AND POTENTIAL ADVERSE EVENTS (OTSG)
1DEC00 ANTHRAX QUARTERLY REPORT
12MAR01 ANTHRAX REPORT FOLLOW–UP QUESTIONS (OTSG)
19MAR01 VARICELLA RATES, 1995–1999 (OTASG)
27MAR01 NUMBER OF VACCINATIONS BY YEAR AND SERVICE (OTSG)
8MAY01 APRIL ANTHRAX REPORT (AMSA)
5JUL01 JULY ANTHRAX/BIRTHDAY ANALYSIS (AMSA)
11JUL01 ANTHRAX QUARTERLY REPORT CODE (AMSA)
30JUL01 JULY ANTHRAX REPORT(AMSA)
5SEP01 ANTHRAX ANTIBODIES SERUM STUDY (AMSA)
21SEP01 ANTHRAX REPORT FOR INSTITUTE OF MEDICINE (SPECIAL ISSUE) (OTSG)
26OCT01 POOL OF CASES FOR ANTHRAX SERUM STUDY (AMSA)
7JAN02 ANTHRAX VACCINATIONS IN DOD BY MONTH (USUHS)
5FEV02 ANTHRAX VACCINATION DATASET (otsg)
14FEB02 VARICELLA COUNTS AND RATES IN AD SOLDIERS—RECRUITS AND NONRECRUITS (CHPPM)
22FEB02 FOLLOW–UP TO ANTHRAX SERUM STUDY (WRAIR)
26FEB02 ANTHRAX IMMUNIZATION DATA REVISITED (OTSG)
7MAY02 AD ARMY WOMEN WITH ANTHRAX VACCINE (AMSA)
8MAY02 OHO—DEPLOYMENT HEALTH OUTCOMES ANALYSIS (AMSA)
8MAY02 QA IMMUNIZATION DATA (AMSA)
16JUL02 BALANCED SCORECARD C1C ANTHRAX IMMUNIZATIONS COMPLIANCE (USACHPPM, ATTN: MCHB–TS-EDE)
19JUL02 DESCRIPTIVE STUDY OF CELLULITIS AMONG U.S. ARMED FORCES,
1998–2001 (MSMR)
29JUL02 DEPLOY FORMS WITH EXPOSURE DATA (USUHS)
5AUG02 PENTAGON DATASET (WRAMC)
8AUG02 ANTHRAX IMMUNIZATION SERUM STUDY (WRAIR)
30AUG02 SLEEP DISORDERS (AMSA)
23SEP02 RE–RUN VA ANNUAL REQUEST FOR DATA ON BOSNIA/KOSOVA VETERANS (VA)
15APR03 30 DAY SERUM FOR SMALLPOX VACCINEES (EXEC SECRETARY, AFEB)16APR03 SUMMARY OF ANTHRAX TOPICS FOR FDA/CDC LIST (CDC)
16APR03 LIVE BIRTHS AND STILLBORNS IN AD WOMEN (FORSCOM)
24APR03 SMALLPOX VACCINATION SURVEILLANCE FOR ADVERSE EVENTS (AVIP AGENCY)
1MAY03 GAO DEPLOYMENT INFO (N=277) (GAO)
6MAY03 AGE DISTRIBUTION OF SMALLPOX VACCINEES WITH SERUM SAMPLES BEFORE AND 7–21 POST (EXEC SEC, AFEB)

6MAY03 VITAMIN D (ASSOCIATED WITH MS STUDY) (HARVARD SCHOOL OF PUBLIC HEALTH)
27MAY03 FOLLOW–UP OF SUMMARY OF ANTHRAX TOPICS FOR FDA/CDC LIST (CDC)
9JUN03 SMALLPOX VACCINATION SURVEILLANCE FOR ADVERSE EVENTS (MSMR)
10JUN03 UPDATE OF HEART DIAGNOSES FOR SMALLPOX (OTSG)
18JUN03 PENTAGON SURVEY OF DE–IDENTIFIED DATA (USACHPPM)
1JUL03 AVAILABLE SERUM AMONG ANTHRAX VACINEES (VACCINE HEALTHCARE CENTER)
15AUG03 VACCINATION FOR ANTHRAX/SMALLPOX AND 3RD PERSCOM (OTSG, POPM)
21AUG03 CONCOMITANT VACCINATIONS RECEIVED WITH SMALLPOX VACCINATION (AVIP AGENCY)
21AUG03 CONGESTIVE HEART FAILURE AMONG SMALLPOX VACCINEES—BEFORE AND AFTER (AMSA)
11MAY04 PEMPHIGUS AUTOANTIBODIES AND ANTHRAX/SMALLPOX VACCINATION (WRAMC)
23JUN04 PEMPHIGUS/ANTHRAX VACCINE SERUM STUDY—GROUP 3 (WRAMC)
23JUN04 PEMPHIGUS/ANTHRAX VACCINE SERUM STUDY—GROUP 1 (WRAMC)
20SEP04 ANTHRAX SERCONVERSION IN AD, BY SERIES SCHEDULE COMPLIANCE (WRAIR DIV OF PM)
19DEC05 PEMPHIGUS/ANTHRAX VACCINE SERUM STUDY—GROUP 2 (SMALLPOX) (WRAMC)
29DEC05 AIR FORCE—YELLOW FEVER VACCINE (YFV) ADVERSE EVENTS (UPDATED ICD–9 CODES) (USUHS)
29DEC05 ARMY, NAVY, MARINE YELLOW FEVER VACCINE ADVERSE EVENTS (UDPATED ICD–9 CODES) (USUHS)
4JAN06 MARINE CORPS OIF Q FEVER SEROCONVERSTION STUDY (FDPMU–WEST)
11JAN06 COUNTS OF INFECTIOUS DISEASES FOLLOWING DEPLOYMENT (CHPPM PAO)
17JAN06 MUMPS CASES PRE–AND POST–DX SERUM (MILVAX)
8MAR06 AIR FORCE DD2796 COMPARISON TO HOGE JAMA PAPER (WRAIR)

Gulf War Illnesses
Testimony to the Senate Veterans Affairs Committee

September 25, 2007

Meryl Nass, MD
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Thank you very much for your invitation to discuss Gulf War Illnesses and ideas for improved research and treatment of affected veterans. I practice general internal medicine, have a background in bioterrorism, anthrax and vaccine injuries, and have conducted a clinic for Gulf War (GW) veterans and others with multi-symptom syndromes (fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivity) since 1999.

Because so much confusion and controversy has surrounded this illness, I thought it would be helpful to discuss persisting issues using a question and answer format, while reviewing recent literature on Gulf War Illnesses. I hope to clarify what is already known, as well as what needs to be known in order to provide the best treatment to affected veterans. I will then discuss my treatment approaches. I use the terms Gulf War Illnesses (GWI) and Gulf War Syndrome (GWS) interchangeably.

1. *What is Gulf War Syndrome?*

As early as 1993, Senator Donald Riegle's staff produced a report that said, "Over 4,000 veterans of the Gulf War suffering from a myriad of illnesses collectively labeled "Gulf War Syndrome" are reporting symptoms of muscle and joint pain, memory loss, intestinal and heart problems, fatigue, running noses, urinary urgency, di-

arrhea, twitching, rashes and sores."[1] In 1998 CDC developed a case definition of the illness, which omits some common symptoms, but confirms the illness Riegle's staff identified, and provides clinicians with a reasonable basis for diagnosing veterans and starting treatment. So there is a long, well-documented history of the reality of this illness.

Yet many physicians are unaware of the CDC case definition, and have been bamboozled by the media into thinking Gulf War Illnesses either do not exist, are psychosomatic or a result of stress. Surprisingly, this includes physicians at VA facilities who care for affected patients. This widespread ignorance is compounded by the VA treatment guidelines (posted on the VA website for clinicians), which emphasize the use of psychotropic medications and cognitive behavioral therapy, although the science to support this is exceedingly weak.[2]

An estimated 200,000 1991 Gulf War veterans (25–30% of all deployed veterans) and some vaccinated, nondeployed Gulf "era" veterans suffer from illnesses related to their service,[3] and have been awarded partial or full disability benefits by the VA. Although the signs, symptoms and severity of illness vary considerably between affected veterans, the combination of symptoms known as "Gulf War Syndrome" probably affects most of the 200,000 veterans who are ill.

Their symptoms are not confined to the CDC's defining triad of musculoskeletal pain, fatigue and cognitive and/or emotional disturbance.[4] Their medical conditions have been variously described in different studies. For example, one UK study found that Gulf War veterans were 20 times as likely as other veterans to complain of mood swings, 20 times as likely to complain of memory loss and/or lack of concentration, and 5 times as likely to complain of sexual dysfunction.[5] It is my opinion that the increased mental disorders reported in GW veterans[6] reflect central nervous system (brain) dysfunction, manifested in a variety of ways.

Furthermore, some affected veterans have developed anxiety and/or depression as a result of their loss of function, as well as frustration resulting from the lack of validation of their illnesses by DOD, VA and civilian health providers, and failure to receive beneficial treatment. Many veterans have endured the suspicion of military superiors and colleagues, friends and family that they are malingering, a result of the mediocre level of much popular and professional discourse about this illness.

2. *Can we make medical sense of the multiple symptoms that occur in Gulf War veterans?*

According to Gronseth, "Although an objective marker to GWS would be useful for studies, the absence of such a marker does not make the syndrome any less legitimate. . . . The real debate surrounding medically unexplained conditions is not whether or not they exist, but defining their cause."[7]

Many patients with GWS meet criteria for other medically unexplained conditions, also known as multi-symptom syndromes, such as chronic fatigue syndrome,[8] fibromyalgia, and multiple chemical sensitivity.[9] These conditions are poorly understood, but have a very similar pattern of symptoms and findings as GWS. Some underlying mechanisms have been shown to be the same as well.[10]

An important VA study in which 1000 deployed 1991 Gulf War and 1000 nondeployed Gulf era veterans were carefully examined 10 years after the Gulf War, found that deployed veterans were 2.3 times as likely to have fibromyalgia, and 40.6

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[1] Staff report to Senator Donald Riegle. Gulf War Syndrome: The case for multiple origin mixed chemical/biotoxin warfare related disorders. September 9, 1993.

[2] Donta ST, Clauw DJ, Engel CC Jr et al. Cognitive behavioral therapy and aerobic exercise for Gulf War veterans' illnesses: a randomized controlled trial. JAMA. 2003 Mar 19;289(11):1396–404.

[3] Steele L. Prevalence and patterns of Gulf War illness in Kansas veterans: association of symptoms with characteristics of person, place, and time of military service. Am J Epidemiol. 2000 Nov 15;152(10):992–1002.

[4] Fukuda, K. et al. Chronic Multi-symptom Illness Affecting Air Force Veterans of the Gulf War. JAMA 1998; 280: 981–988. ". . . a case was defined as having 1 or more chronic symptoms (more than 6 months) from 2 of the following categories: fatigue; mood and cognition; and musculoskeletal."

[5] Simmons R, Maconochie N, Doyle P. Self-reported ill health in male UK Gulf War veterans: a retrospective cohort study. BMC Public Health. 2004 Jul 13;4:27.

[6] Toomey r, Kang HK, Karlinsky J et al. Mental health of U.S. Gulf War veterans 10 years after the war. Br J Psychiatry 2007; 190: 385–93.

[7] Gronseth GS. Gulf War syndrome: a toxic exposure? A systematic review. Neurol Clin. 2005 May;23(2):523–40.

[8] Thomas HV, Stimpson NJ, Weightman AL et al. Systematic review of multi-symptom conditions in Gulf War veterans. Psychol Med 2006; 36: 735–47.

[9] Ibid.

[10] Baraniuk JN, Casado B, Maibach HA. Chronic Fatigue Syndrome—related proteome in human cerebrospinal fluid. BMC Neurol. 2005 Dec 1;5:22.

times as likely to have chronic fatigue syndrome as nondeployed era veterans,[11] confirming a relationship between these conditions and GWS.

3. *Does the CDC case definition identify all deployment-related illnesses in Gulf War veterans?*

No. We know ALS (amyotrophic lateral sclerosis or Lou Gehrig's disease) occurs twice as often in GW vets as in the civilian population, but it also occurs 50% more often in soldiers in general.[12] The military exposures leading to these increased ALS rates are unknown.

Possible reasons ALS has been studied more carefully in GW veterans than other illnesses, are that a) veterans develop the illness at a younger age than the civilian population,[13] b) Congressional testimony by affected, now deceased Gulf War veteran Michael Donnelly in 1997 gave the illness visibility,[14] and c) ALS only affects a small number of people.

Chronic diarrhea is another illness commonly seen in GW veterans, but it is not included in the CDC's case definition. GW veterans have developed a variety of other medical illnesses. What we still don't know is whether there are, for instance, more heart attacks in deployed GW veterans than there would have been, had they not deployed. The research is contradictory on whether various illnesses occur more often in Gulf War veterans, although several studies list a large number of symptoms that are seen more commonly in GW veterans.

4. *Why don't we know whether deployed veterans have more illnesses (like heart attacks) than they would have otherwise?*

The results of research depend on the methods used to investigate the research question. Epidemiological research is limited to evaluating a statistical relationship between an exposure and an illness. But statistically significant relationships occur for many reasons other than cause and effect. Thus, statistics alone cannot prove cause and effect. Only when all other factors that can bias the result have been taken into account, will the results be reliable. Here is one example of why some Gulf War research results may be contradictory:

As Steele[15] showed, many nondeployed Gulf "era" veterans were given vaccinations in preparation for deployment, and these vaccinated "era" veterans reported multi-symptom illness at 3 times the rate of unvaccinated, nondeployed "era" veterans.

According to the military's Defense Medical Surveillance System (DMSS) raw data, soldiers vaccinated with anthrax vaccine have heart attacks at a greater rate than prior to vaccination.[16] Thus, if deployed veterans are compared to a nondeployed group, of whom many received deployment vaccines, determining whether deployed veterans have more heart attacks than expected is confounded (made unreliable) by the nondeployed group's vaccinations.

Military and VA health databases have not been made available to independent researchers to study.

5. *Has the health of Gulf War veterans improved over time?*

Veterans who developed this syndrome have, for the most part, remained ill.[17] Ten years later, one study found that 29% of deployed veterans had chronic, multisymptom illness.[18]

6. *Do GW veterans die at a higher rate?*

Three studies have demonstrated that GW veterans had an approximately 50% greater risk of accidental deaths, particularly from motor vehicle accidents. Although this has been attributed to elevated risk-taking behavior in deployed GW

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[11] Eisen SA, Kang HK, Murphy FM et al. Gulf War veterans' health: medical evaluation of a U.S. cohort. Ann Intern Med 2005; 142: 122.

[12] Weisskopf MG, O'Reilly EJ, McCullough ML et al. Prospective study of military service and mortality from ALS. Neurology 2005;64(1):32–7.

[13] Haley RW. Excess incidence of ALS in young Gulf War veterans. Neurology. 2003 Sep 23;61(6):750–6.

[14] http://members.aol.com/vetcenter1/donnelly.htm

[15] Steele L. Prevalence and patterns of Gulf War illness in Kansas veterans: association of symptoms with characteristics of person, place, and time of military service. Am J Epidemiol. 2000 Nov 15;152(10):992–1002.

[16] Data DOD shared with the Institute of Medicine in 2001: http://merylnass.googlepages.com/AMSAtitlepage.pdf http://merylnass.googlepages.com/AMSAHeartattackdata.pdf

[17] Ozakincy G, Hallman WK and Kipen HM. Persistence of symptoms in veterans of the First Gulf War: 5-year followup. Environ Health Perspectives 2006; 114: 1553–7.

[18] Blanchard MS, Eisen SA, Alpern R et al. Chronic multisymptom illness complex in Gulf War 1 veterans 10 years later. Am J Epidemiol 2006; 164: 708–9

soldiers by some, others (including myself) suspect it is at least partly related to the cognitive problems faced by GW veterans, particularly their difficulties with attention and concentration.

One study found that testicular cancer rates were increased in Persian Gulf War veterans.[19] This is usually a curable cancer that occurs in young males, so would not be expected to increase overall mortality rates significantly.

Other statistical studies have shown no more deaths and no more birth defects in offspring of GW soldiers than in comparable groups. However, was the control group truly comparable? Deployed troops are known to be much healthier than a group of age and sex-matched civilians, and this is commonly termed the "Healthy Warrior" effect. But they may also be healthier than the Gulf "era" troops who were not deployed, although "era" troops usually form the comparison group.

Steele showed that in Kansas veterans, the rate of multi-symptom illness varied by deployment location.[20] Since different units had very varied exposures during their deployments, high rates of birth defects and/or deaths in certain units are possible. Yet the types of large epidemiological studies that have been performed have usually obscured possible localized effects of service in the Gulf.

7. *Self reports*

The validity of studies of GW veterans' health and exposures has been criticized on the basis that the exposure and illness data are reported by veterans, and not obtained from more reliable sources, such as military or VA databases. Some measures of current health could be obtained from those databases, but the data would be incomplete. Exposure data have not been a part of the available record for most veterans. Exposure data that have been supplied by DOD have been unreliable (in terms of the Khamisiyah plume modeling, according to GAO[21]) or the data contradicted the self-reports (as in immunization data supplied by DOD to VA, following presentation of a VA study that linked anthrax vaccinations to subsequent ill health[22]), or the data are missing or classified. The number, names and locations of all sites at which chemical warfare agents were exploded remain unknown to the public.

Are self-reports valid? Two recent studies indicate that GW veterans give reliable answers to questions.[23] A study that compared GW veterans with Gulf era veterans' performance on neuropsychological examinations found that only 1% of GW veterans provided "noncredible" exams versus 4% of era veterans.[24] Therefore, self-reports by GW veterans can safely be judged credible.

8. *Why has the reality of Gulf War Syndrome been so contentious?*

Perhaps remarks by Alabama Congressman Glen Browder in a 1993 House Armed Services Oversight and Investigations Subcommittee meeting shed some light on this:

> "I have asked a lot of questions about why the Pentagon continues to stonewall these Gulf War veterans, or why are they so resistant to full and open examination of this problem. I don't have any conclusive answers but I can speculate.
>
> First, it may be pride. To acknowledge these mystery casualties may blemish our Persian Gulf victory. Or, such an acknowledgement may be a terrifying ad-

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[19] Levine PH, Young HA, Simmens SJ et al. Is testicular cancer related to Gulf War deployment? Evidence from a pilot population-based study of Gulf War veterans and cancer registries. Mil Med 2005: 170: 149–53.

[20] Steele L. Op. cit.

[21] GAO–04–821T. June 1, 2004: "The modeling assumptions . . . were inaccurate because they were uncertain, incomplete and nonvalidated." "DOD and VA's conclusions about no association between exposure to CW agents and rates of hospitalization and mortality . . . cannot be adequately supported because of study weaknesses."

[22] Mahan CM, Kang HK, Dalager NA Anthrax vaccination and self-reported symptoms, functional status, and medical conditions in the National Health Survey of Gulf War Era Veterans and Their Families. Ann Epidemiol. 2004 Feb;14(2):81–8.

[23] Kelsall HL, Sim MR, Forbes AB et al. Symptoms and medical conditions in Australian veterans of the 1991 Gulf War: relation to immunisations and other Gulf War exposures. Occup Environ Med. 2005 Mar;62(3):142–3. "More than 10 years after the 1991 Gulf War, Australian veterans self-report all symptoms and some medical conditions more commonly than the comparison group. Further analysis of the severity of symptoms and likelihood of the diagnosis of medical conditions suggested that these findings are not due to over-reporting or to participation bias."

[24] Barrash J, Denburg NL, Moser DJ et al. Credibility of neuropsychological performances of Persian Gulf War veterans and military control subjects participating in clinical epidemiological research. Mil Med 2007; 172: 697–707.

mission that the United States did not and perhaps cannot protect our military men and women against chemical and biological warfare.

But I personally suspect that dealing openly and fully with these mystery ailments, and therefore the dirty little secret, will require the Pentagon to make budgetary and programmatic adjustments that it does not want to make."[25]

Military doctrine calls for continuing use of anthrax and smallpox vaccines, multiple simultaneous vaccinations, pyridostigmine bromide tablets for prophylaxis of nerve gas exposure and depleted uranium munitions and armor. Thus military studies that concluded these exposures were safe should come as no surprise. Yet evidence of their adverse effects on health is abundant.

The American Type Culture Collection (ATCC) supplied various microbial cultures to Iraq, in shipments approved by the Department of Commerce, during a period in which the United States assisted Iraq in its war with Iran. This may have influenced why infections due to Brucella melitensis, one of the bacteria provided to Iraq, were not investigated. Vollum[26] strain anthrax (which had been weaponized by the U.S. military before the Biological Weapons Convention came into force in 1975) was provided to Iraq by ATCC. Knowing a U.S. corporation provided Iraq virulent anthrax (not a strain used to make vaccines) may have influenced the defense department's decision to vaccinate troops against anthrax. Similarly, the ATCC provided Clostridium botulinum to Iraq; some soldiers were later vaccinated for potential exposure to botulinum toxins.

Admitting that soldiers became ill as a consequence of what the U.S. gave Iraq may be politically unacceptable, undermining the likelihood that credible scientific studies of these exposures, funded by the government, would be performed.

According to the House Committee on government Reform and Oversight in 1997, *"VA medical policy may have been biased against findings of chemical exposure by relying on DOD assertions and unproven theories of toxic causation. VA continues today to maintain that chronic symptoms in Gulf War veterans cannot be attributed to toxic exposures unless acute symptoms first appear at the time of exposure."*[27]

Yet the requirement for acute symptoms to occur in order to be harmed by chemical weapons (organophosphates) is scientifically insupportable.

Investigating certain GW exposures has been a career killer. While some researchers were amply rewarded for finding stress/psychological causes for Gulf War Illnesses, other researchers were punished for exploring politically unacceptable causes:

- Jim Moss, PhD on pyridostigmine potentiation research: "Middle and upper level management at USDA promised me I would be blackballed if I did not stop the research, or if I ever disclosed my research to anybody (this was before I appeared before the Senate VA committee). My biggest regret from my 1994 Senate VA Committee testimony has been that I did not tell the Committee about the threats."[28,29]
- Charles Gutierrez, MS found microorganisms resembling Brucella melitensis in stools of dozens of Gulf War veterans in Tennessee, but had his studies halted: "In the years following the Persian Gulf War, extensive clinical studies on samples from Persian Gulf War veterans were performed at the James Quillen VA in Mountain Home, Tennessee. This work was not adequately pursued by the VA, and was instead ordered stopped. The findings in these patients need to be addressed, as they may fill in gaps in the existing body of GW illness research."[30]
- Garth Nicolson, PhD on mycoplasma studies: "I was told by the President of my institution (the Univ. of Texas M.D. Anderson Cancer Center) to stop my GWI research or face disciplinary action. I refused to stop my research, and my professional career, academic position (and any possible future academic position) were destroyed by character assignation and outright lies about my research ac-

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[25] Use of chemical weapons in Desert Storm. Hearing before the Oversight and Investigations Subcommittee of the Committee on Armed Services, House of Representatives. 103d Congress, 1st session. November 18, 1993.

[26] Identified by Geoffrey Holland, who investigated the provenance of the ATCC anthrax strains supplied to Iraq. www.abc.net.au/worldtoday/content/2005/s1434633.htm

[27] House Committee on government Reform and Oversight. Gulf War Veterans' Illnesses: VA, DOD continue to resist strong evidence linking toxic causes to chronic health effects. November 7, 1997. House Report 105–388. 105th Congress, 1st Session.

[28] Personal communication, September 17, 2007

[29] Chaney LA, Rockhold RW, Mozingo JR, Hume AS, Moss JI.Potentiation of pyridostigmine bromide toxicity in mice by selected adrenergic agents and caffeine. Vet Hum Toxicol. 1997 Aug;39(4):214–9.

[30] Personal communication, September 17, 2007

tivities. This occurred even though our work was published in peer-reviewed academic journals. This was described in our book Project Day Lily (www.projectdaylily.com)."[31,32,33]

9. *How is it that Federal public health "watchdog" agencies and oversight mechanisms failed to prevent the public health disaster of GWS?*

Federal agencies that could have weighed in on the safety of drugs and vaccines given to soldiers in the Gulf have become politicized, and their decisionmaking processes are opaque. The regulation of toxic substances is fragmented, overseen by a variety of agencies. Recent FDA decisions, and the agency's structure, suggest safety has a low priority.

- FDA permitted use of unlicensed drugs and vaccines, and use of licensed products for unproven purposes, during the Gulf War and later
- FDA repeatedly approved anthrax vaccine use for bioterrorism preparedness in the absence of required human data demonstrating effectiveness, and despite ample evidence of safety concerns
- Astonishingly, FDA drug and vaccine safety experts have no regulatory authority[34]
- FDA "safety experts work largely in isolation, with limited resources and outdated technology."[35]
- "The FDA has bungled its effort to build a new system for detecting the side effects of medicines after they go on the market, delaying its implementation by at least 4 years, according to a report commissioned by the agency itself . . . the FDA has wasted an estimated $25 million on its efforts."[36]
- CDC continues to misinform recipients of anthrax vaccine with an official Vaccine Information Statement affirming vaccine safety that is in conflict with the vaccine's FDA-approved package insert,[37] and what CDC officials told GAO about adverse events following vaccination. The GAO, citing CDC and Vaccine Healthcare Center officials as sources, reported that 1–2% of anthrax-vaccinated individuals "may experience severe adverse events, which could result in disability or death," in June 2007.[38]
- CDC conducted a trial of anthrax vaccine in 1564 people beginning in 2002 and provided an interim report on the study to FDA. Yet CDC has released no information to the public about the trial findings, despite filing over 100 adverse event reports on trial subjects to the Vaccine Adverse Event Reporting System.
- These federal agencies know that injured military servicemembers are prevented by the Feres Doctrine[39] from seeking a remedy for their injuries through the legal system.
- There are no viable legal remedies to hold military or government personnel accountable for deliberate cover-ups resulting in denial of healthcare and disability benefits mandated by Federal law.

10. *What Gulf War exposures did soldiers face, and what do we know about the injuries they may cause?*

a. *Depleted uranium (DU)*

DU is comprised of uranium that has had 40% of its radioactive isotope, uranium-235, extracted. However, the DU used by the United States military also contains

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[31] Personal communication, September 17, 2007

[32] Nicolson GL, Nasralla MY, Haier J, Pomfret J. High frequency of systemic mycoplasmal infections in Gulf War veterans and civilians with Amyotrophic Lateral Sclerosis (ALS). J Clin Neurosci. 2002 Sep;9(5):525–9.

[33] Nicolson GL and Nicolson NL. Diagnosis and treatment of mycoplasmal infections in persian Gulf War llness illness-cfids patients. Journal of Occupational Medicine, Immunology and Toxicology 5: 69–78, 1996.

[34] Smith SW. Sidelining safety-the FDA's inadequate response to the IOM. NEJM September 6, 2007. 960–3.

[35] Ibid.

[36] Mathews AW. Report blasts FDA's system to track drugs. Consultant says mission is hobbled by missteps; agency disputes claims. Wall Street Journal. March 3, 2007. A1.

[37] http://www.fda.gov/OHRMS/DOCKETS/98fr/05n-0040-bkg0001.pdf

[38] GAO–07–787R. Military Health: DOD's Vaccine Healthcare Centers Network. June 29, 2007. Web address: http://www.gao.gov/cgi-bin/getrpt?GAO-07-787R

[39] http://usmilitary.about.com/library/milinfo/blferes.htm

"recycled" nuclear reactor waste, including small amounts of highly radioactive plutonium-239, neptunium-237, technicium-99, americium etc.[40,41]

Both munitions and armor may be made from DU. When a DU munition strikes an object, or when DU armor is struck, it ignites and up to 50% of its mass can aerosolize into minute particles that may be inhaled and will contaminate the area for the foreseeable future. Inhaled DU may have prolonged retention in the lungs, accumulates in specific brain regions (in rat experiments)[42] and settles in bone. Inhaled DU led to behavioral effects in animals.[43] It is excreted by the kidneys. Its toxicity is both chemical and radiological.

The only veterans who have been studied longitudinally for DU exposure comprise a small group with embedded DU shrapnel. They have shown limited findings of genotoxicity and are otherwise well,[44] but have a "relatively low uranium burden compared to historical uranium-exposed controls."[45] However, other veterans with inhalation exposures are probably at greater risk of DU toxicity. One study found that reported exposure to DU doubled the risk of dying from disease.[46] (Reported pesticide exposure in this study doubled the likelihood of accidental death.)

Consider that the recycled nuclear materials added to DU may not be evenly dispersed. If so, there are likely some veterans with greater exposure to highly radioactive materials, who are at increased risk of cancers, immune and reproductive effects. Recent evidence also points to uranium as an endocrine disruptor.[47]

If we review the health of workers in uranium processing plants, we can obtain clues about what to expect in DU-exposed veterans. Uranium workers have had elevated rates of cancers, especially kidney and respiratory tract cancers. They also had elevated levels of chronic kidney disease.

The Energy Employee Occupational Illness Compensation Program Act of 2000 (P.L. 106–398) established a "special cohort" of workers employed at three Department of Energy uranium gaseous diffusion plants and Alaska's nuclear test site: because of the absence of exposure records, and the presence of ultra hazardous workplace exposures, the burden of proof has been shifted to the government for ill workers at these facilities.[48] The combination of an ultra hazardous workplace and absent exposure records[49] mirrors the plight of Gulf War veterans, and suggests to us that burden of proof requirements could be changed for veterans who suffer from illnesses characteristic of their toxic exposures.

"Personal medical records of veterans, including sick call records, are inadequate or missing. Documents which could help verify possible exposures and military unit locations remain in DOD files. Most of the military NBC logs, which are records of toxic warfare agent detections, are missing or destroyed. . . ."

b. *Sarin*

Sarin is an organophosphate "nerve" agent or anticholinesterase, which leads to excessive accumulation of the neurotransmitter acetylcholine at nerve synapses. It is in the same family as pesticides such as parathion and malathion. A recent study found a significant association between levels of estimated sarin/cyclosarin exposure and reduced white matter in the brain.[50] The same researchers also found that

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[40] http://www.nato.int/du/docu/d010118b.htm

[41] Alvarez R. The legacy of depleted uranium in the United States. Institute for Policy Studies monograph. June 2003.

[42] Fitsanakis VA, Erickson KM, Garcia SJ et al. Brain accumulation of depleted uranium in rats following 3- or 6-month treatment with implanted depleted uranium pellets. Biol Trace Elem Res 2006; 111: 185–97.

[43] Monleau M, Bussy C, Lestaevel P et al. Bioaccumulation and behavioural effects of depleted uranium in rats exposed to repeated inhalations. Neurosci Lett. 2005 Dec 16;390(1):31–6.

[44] McDiarmid MA, Engelhardt SM, Oliver M et al. Health surveillance of Gulf War 1 veterans exposed to depleted uranium: updating the cohort. Health Phys 2007; 93: 60–73.

[45] McDiarmid MA, Engelhardt SM, Oliver M et al. Biological monitoring and surveillance results of Gulf War 1 veterans exposed to depleted uranium. Int Arch Occup Envir Health 2006; 79:11–21.

[46] MacFarlane GJ, Hotopf M, Maconochie N et al. Long-term mortality amongst Gulf War veterans: is there a relationship with experiences during deployment and subsequent morbidity? Int J Epidemiol 2005; 34: 1403–8.

[47] Raymond-Whish S, Mayer LP, O'Neal T et al. Drinking water with uranium below U.S. EPA water standard causes estrogen receptor-dependent responses in female mice. Envir Health Perspectives 2007; online September 14, 2007.

[48] Alvarez R. Op. cit.

[49] Committee on government Reform and Oversight. Gulf War Veterans' Illnesses: VA, DOD continue to resist strong evidence linking toxic causes to chronic health effects. Second Report. November 7, 1997. 105th Congress, 1st session. Page 61.

[50] Heaton KJ, Palumbo CL, Proctor SP et al. Quantitative magnetic resonance brain imaging in U.S. veterans of the 1991 Gulf War potentially exposed to sarin and cyclosarin. Neurotoxicology 2007 28:761–9.

"Sarin and cyclosarin exposure was associated with less proficient neurobehavioral functioning on tasks involving fine psychomotor dexterity and visuospatial abilities 4–5 years after exposure."[51]

According to the Congressional Office of Technology Assessment (OTA) in 1990:

> "Of particular concern are the delayed neurotoxic effects of some of the organophosphorous (organophosphate) insecticides. Some of these compounds cause degeneration of nerve processes in the limbs, leading to changes in sensation, muscular weakness and lack of coordination. Because of this property, the EPA requires that organophoshorous insecticides undergo special testing for delayed neurotoxicity."[52]

Thus despite claims by DOD that lack of acute sarin toxicity precluded later disease, it was common knowledge at the time of the 1991 Gulf War that delayed adverse effects do occur from exposure to this class of compounds.

Furthermore, a VA study of mortality in 100,000 veterans said to be exposed to sarin at Khamisiyah found a statistically significant doubling of deaths from brain cancer in the exposed group, compared to unexposed Gulf War veterans, as well as a limited dose-response relationship.[53]

According to a popular toxicology textbook, anticholinesterases may cause "drowsiness, lethargy, fatigue, mental confusion, inability to concentrate, headache, pressure in head, generalized weakness."[54]

c. *Other pesticides*

Carbamate pesticides were used in the Gulf and also cause acetylcholine accumulation. They would augment the adverse effects of sarin and organophosphate insecticides. Organochlorine and pyrethrin insecticides have different mechanisms of action, but are also toxic to the peripheral and central nervous system, so their adverse effects might compound those of the anticholinesterases. Some pesticides have adverse immunotoxic effects as well.[55] A recent review by NIH's National Institute of Environmental Health Sciences researchers discussed the state of knowledge of pesticide toxicity, and suggested that general malaise associated with mild cognitive dysfunction may be a sensitive marker for pesticide neurotoxicity.[56]

d. *Organic Solvents*

These include jet and vehicle fuels, some cleaning agents and other industrial chemicals. According to the Office of Technology Assessment:

"Acute exposure to organic solvents can affect an individual's manual dexterity, response speed, coordination and balance. Chronic exposure of workers may lead to reduced function of the peripheral nerves and such adverse neurobehavioral effects as fatigue, irritability, loss of memory, sustained changes in personality or mood, and decreased ability to learn and concentrate."[57]

Therefore, sarin nerve gas, organophosphate and other pesticides, and solvents have the potential to induce the neurological and neurobehavioral effects seen in Gulf War veterans. This was known prior to the first Gulf War.

e. *Endemic diseases and/or biological weapons exposures*

It remains unknown whether troops faced any biological attacks. Exposure to novel microorganisms has never been ruled out. The role of infections endemic to the middle east in Gulf War Illnesses is also unknown. The following three microorganisms probably infected some Gulf War veterans, but other microorganisms may also contribute to GWI.

- Leishmaniasis, due to a parasite spread by the sandfly, is endemic in Iraq, but the visceral form of the disease is difficult to diagnose. Until better diagnostics

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[51] Proctor SP, Heaton KJ, Heeren T et al. Effects of sarin and cyclosarin exposure during the 1991 Gulf Waar on neurobehavioral functioning in U.S. Army veterans. Neurotoxicology 2006; 27: 931–9.

[52] Congressional Office of Technology Assessment. Neurotoxicity: Identifying and controlling poisons of the nervous system. April 1990. OTA–BA–436. Page 50.

[53] Bullman TA, Mahan CM, Kang HK et al. Mortality in U.S. Army Gulf War veterans exposed to 1991 Khamisiyah chemical munitions destruction. Am J Public Health 2005; 95:1382–8.

[54] Klaassen CD. Cassarett and Doull's Toxicology. 5th edition, 1996. McGraw Hill, N.Y. p.657.

[55] Congressional Office of Technology Assessment. Identifying and controlling immunotoxic substances. Neurotoxicity: Identifying and controlling poisons of the nervous system. April 1990. OTA–BA–436. government Printing Office. 1991.

[56] Kamel F and Hoppin JA. Association of pesticide exposure with neurologic function and disease. Environ Health Perspect. 2004 Jun;112(9):950–8.

[57] Congressional Office of Technology Assessment. 1990. Op. cit. page 30

are available, it is certain that cases will be missed. It can take months or even years to develop symptoms, and leishmaniasis may develop into a chronic, debilitating illness.

- Brucella melitensis is both endemic to Iraq and a potential biological warfare agent. It can cause a slowly developing, fatiguing illness with a variety of possible signs and symptoms, especially joint pain and fever. It is difficult to diagnose because standard tests usually miss it, so unless it is considered in the differential diagnosis and special tests ordered, it will be overlooked.
- Mycoplasmas have been linked to chronic multisymptom illnesses.[58] They are widely distributed, and the known spectrum of clinical illness they cause continues to expand.[59] A significant percentage of GW veterans have antibodies to mycoplasma.

f. *Contaminated water*

Possible contaminants include endemic or deliberately added microorganisms and petroleum products. Soldiers reported that some storage tanks supplying drinking water were also used for vehicle fuels, and the water contained fuel residues.

g. *Smoke from oil well fires*

Little reliable data on the contents and concentrations of materials comprising the oil well fire smoke is available.[60] Toxic inhalants could have been burned deliberately by retreating Iraqi troops.

h. *Pyridostigmine bromide (unlicensed use) a.k.a. PB, NAPPS*

Also increases acetylcholine at nerve synapses; will augment the adverse effects of sarin, organophosphate and carbamate insecticides. Multiple studies have linked PB use to later illness in GW troops.[61]

i. *Other unlicensed drugs approved for use in the Gulf theater*[62]

- **Centoxin (J5 monoclonal antibody),** purchased by the military, prior to licensure of the drug, to treat sepsis in Gulf War veterans. Found later to increase mortality rates in treated patients.[63,64] Never licensed.
- **Ribavirin,** purchased by the military for use in unspecified viral illnesses. Yet when used later as an experimental treatment for SARS, Ribavirin produced anemia, bradycardia and hypomagnesemia, increasing mortality.[65] Other researchers later noted, "Ribavirin should not be used empirically for the treatment of viral syndromes of unknown etiology."[66] Ribavirin also causes immunotoxicity.[67] Its adverse reactions include fatigue and depression, which may persist after the drug is stopped.

j. *Electromagnetic fields*

Electromagnetic weapons, including high power microwaves,[68] were used to disrupt and destroy Iraqi electronic systems. Generation of electromagnetic fields may have been used for other effects, and for communication. Whether electromagnetic fields contributed to illness is unknown, as are the types and magnitudes of the exposures. However, the European Union's European Environment Agency has just called for immediate action to reduce exposure to microwaves, following an inter-

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[58] Nasralla M, Haier J, Nicolson GL. Multiple mycoplasmal infections detected in blood of patients with chronic fatigue syndrome and/or fibromyalgia syndrome. Eur J Clin Microbiol Infect Dis. 1999; 18(12):859–65.

[59] Baseman JB, Tully JG. Mycoplasmas: sophisticated, reemerging, and burdened by their notoriety. Emerg Infect Dis. 1997 Jan-Mar; 3(1):21–32.

[60] Committee on government Reform and Oversight. Gulf War Veterans' Illnesses: VA, DOD continue to resist strong evidence linking toxic causes to chronic health effects. Second Report. November 7, 1997. 105th Congress, Ist session. Page 67.

[61] Schumm, W. R., Reppert, E. J., Jurich AP et al. Pyridostigmine bromide and the long-term subjective health status of a sample of over 700 male Reserve Component Gulf War era veterans. Psychological Reports 2002; 90: 707–721.

[62] Rettig R. Military use of drugs not yet approved by the FDA for CW/BW defense. RAND Monograph on Lessons from the Gulf War. 1999.

[63] Shulman R. Current drug treatment of sepsis. Hospital Pharmacist 2002; 9: 97–101.

[64] Quezado ZM, Natanson C, Alling DW et al. A controlled trial of HA–1A in a canine model of gram-negative septic shock. JAMA 1993; 269: 2221–7.

[65] Chiou HE, Liu CL, Buttrey MJ et al. Adverse effects of ribavirin and outcome in severe acute respiratory syndrome in two medical centers. Chest 2005; 128:263–72.

[66] Muller MP, Dresser L, Raboud J et al. Adverse events associated with high-dose ribavirin: evidence from the Toronto outbreak of severe acute respiratory syndrome. Pharmacotherapy 2007; 27: 494–503.

[67] Office of Technology Assessment. Identifying and controlling immunotoxic substances. April 1991. OTA–BP-BA–75.

[68] http://www.globalsecurity.org/military/systems/munitions/hpm.htm

national scientific review, which concluded that safety limits set for the radiation are "thousands of times too lenient." [69]

k. *Vaccines*

- **Botulinum toxoid vaccine,** manufactured by Michigan Department of Public Health, meant to immunize against botulinum toxins. The toxins block neurotransmission, as does the toxoid. Never licensed. Very little known about safety or efficacy.
- **Anthrax vaccine,** licensed with inadequate data. Concentration increased 100 times due to manufacturing changes at the time of the Gulf War. Identified as a risk factor for Gulf War illnesses by multiple studies.[70,71,72,73,74] The vaccine's package insert lists the CDC definition of Gulf War Syndrome as a reported adverse event following anthrax vaccine. Many of the over 5,000 reports to the Vaccine Adverse Event Reporting System of FDA–CDC for anthrax vaccine indicate chronic illnesses whose symptoms resemble GWS. I have treated many soldiers who became ill following anthrax vaccine given since the 1991 Gulf War, and the majority experience cognitive impairment, generalized pain and fatigue, among other symptoms, meeting the CDC's case definition for GWS. See my testimony to the House Veterans Affairs Health Subcommittee for additional information.[75]
- **Multiple vaccines given together within a short time period.** Are multiple simultaneous vaccinations dangerous? Although the question has been discussed by the Institute of Medicine, the Armed Forces Epidemiology Board and the British Ministry of Defense, they provide no conclusive answer. Studies of multiple vaccinations associated with Gulf War Illnesses have shown a positive, dose-response relationship, suggesting they did contribute to GWI.[76,77] Soldiers engaged in Operation Iraqi Freedom have also reported Gulf War Illness-like disease following multiple vaccinations, with both acute and chronic effects.[78] British military policy now separates anthrax and smallpox vaccinations from other vaccinations by at least 5 days.[79]

11. ***What can we conclude about the exposures?***

a. Several of the exposures can individually produce the symptoms GW veterans are experiencing. Injuries from these substances can affect cognition, emotion, motor and sensory function. These include sarin, pesticides, solvents, anthrax vaccine and some chronic infections, at a minimum.

b. Combined exposures to certain toxic substances (and simultaneous exercise) greatly magnify the potential for adverse reactions:

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[69] Lean G. EU calls for urgent action on wi-fi radiation. New Zealand Herald. September 16, 2007. http://www.nzherald.co.nz/section/2/story.cfm?c_id=2&objectid=10463870

[70] Unwin C, Blatchley N, Coker W, Ferry S, Hotopf M, Hull L, et al. Health of UK servicemen who served in Persian Gulf War. Lancet. 1999 Jan 16; 353(9148):169–78.

[71] Goss-Gilroy. Study of Canadian Gulf War Veterans: NR–98.050. Study contracted by the Canadian Department of National Defense, released June 29, 1998 and published on its website, accessed between 1999 and 2001 but no longer at the previous URL: http://www.dnd.ca/menu/press/Reports/Health/health_study_eng_1.htm.

[72] Schumm WR, Reppert EJ, Jurich AP et al. Self-reported changes in subjective health and anthrax vaccination as reported by over 900 Persian Gulf War era veterans. Psychol Rep. 2002 Apr;90(2):639–53.

[73] Boyd KC, Hallman WK, Wartenberg D, Fiedler N, Brewer NT, Kipen HM. Reported exposures, stressors, and life events among Gulf War Registry veterans. J Occup Environ Med. 2003 Dec;45(12):1247–56.

[74] Wolfe J, Proctor SP, Erickson DJ, Hu H. Risk factors for multisymptom illness in U.S. Army veterans of the Gulf War. J Occup Environ Med. 2002 Mar;44(3):271–81.

[75] http://merylnass.googlepages.com/writtentestimony7-26-07.doc

[76] Kelsall HL, Sim MR, Forbes AB et al. Symptoms and medical conditions in Australian veterans of the 1991 Gulf War: relation to immunisations and other Gulf War exposures. Occup Environ Med. 2004 Dec;61(12):1006–13.

[77] Cherry N, Creed F, Silman A ET AL. Health and exposures of United Kingdom Gulf War veterans. Part II: The relation of health to exposure. Occup Environ Med. 2001 May;58(5):299–306.

[78] http://www.bmj.com/cgi/content/full/326/7401/1234-a
Dyer O. Ministry of Defence accused of contravening inoculation guidelines. BMJ 2003;326:1234.

[79] Ibid

- Somani et al. Exercise plus Pyridostigmine Bromide amplified oxidative injury in skeletal muscle of mice.[80]
- Abou-Donia et al. "These results suggest that exposure to real-life doses of malathion, DEET and permethrin, alone or in combination, produce no overt signs of toxicity but induce significant neurobehavioral deficits and neuronal degeneration in brain."[81]
- McCain et al. "A significant increase in lethality occurred when PB, permethrin and DEET were given concurrently, when compared to expected additive values."[82]
- Haley RW et al. "Some Gulf War veterans may have delayed, chronic neurotoxic syndromes from wartime exposure to combinations of chemicals that inhibit butyrylcholinesterase and neuropathy target esterase."[83]

Haley RW, Kurt TL. JAMA. 1997 Jan 15;277(3):231–7.

c. Multiple simultaneous vaccinations increased the risk of GWS.
d. For some other exposures, there is very little available information on toxicity.
e. Depleted uranium likely contributed to chronic illnesses (and deaths in soldiers tasked to clean up DU.)[84]
f. Illnesses resulting from infections, electromagnetic fields, smoke, drugs and possibly other exposures have not been ruled out in GW veterans.

12. *What is known about underlying pathology in GWS?*

a. Autonomic nervous system function has been shown to be altered in Gulf War veterans in multiple studies, as has hypothalamic pituitary adrenal function.[85]
b. Altered immune function reflects another aspect of this disorder for many veterans.[86]
c. One's genes affect the speed of processing of toxic substances and later manifestation of toxic effects.[87]
d. Gulf War soldiers encountered an unprecedented mix of noxious substances, which are known to cause neurological, immunologic and other adverse effects. Gulf War Illness research even suggests a dose-response relationship between some exposures and symptoms.[88]

***A very reasonable hypothesis is that those who became ill reached a tipping point, where their body's ability to safely process the toxic materials they took in was exceeded. Chronic illness may have resulted from tissue damage (such as permanent loss of neurons) and/or persisting metabolic abnormalities, which have yet to be defined, but are suspected to include impaired oxidative phosphorylation[89,90] and/or other fundamental changes in body chemistry that can affect multiple organ systems.**

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[80] Jagannathan R, Husain K and Somani SM. Interaction of pyridostigmine and physical stress on antioxidant defense system in skeletal muscle of mice. J App; Toxicol 2001; 21: 341–8.

[81] Del-Rahman A, Dechkovskaia AM, Goldstein LB et al. Neurological deficits induced by malathion, DEET and permethrin, alone or in combination in adult rats. J Toxicology and Environmental Health 2004; 67: 331–356.

[82] McCain WC, Mark RL, Johnson JS et al. Acute oral toxicity study of pyridostigmine bromide, permethrin, and DEET in the laboratory rat. J Toxicology and Environmental Health 1997; 50: 113–124.

[83] Self-reported exposure to neurotoxic chemical combinations in the Gulf War. A cross-sectional epidemiologic study.

[84] Doug Rokke, PhD. Personal communication September 18, 2007.

[85] Clauw D, Groner G, Whalen K. Hypothalamic pituitary adrenal function in veterans with unexplained illness, compared to fibromyalgia subjects and controls. Presented at the Conference on Illnesses among Gulf War veterans: A decade of scientific research. January 24–26, 2001. Alexandria, VA.

[86] Zhang Q, Zhou XD, Denny T et al. Changes in immune parameters seen in Gulf War veterans but not in civilians with chronic fatigue syndrome. Clin Diagn Lab Immunol. 1999 Jan;6(1):6–13.

[87] Haley RW, Billecke S, La Du BN. Association of low PON1 type Q (type A) arylesterase activity with neurologic symptom complexes in Gulf War veterans. Toxicol Appl Pharmacol. 1999 Jun 15;157(3):227–33.

[88] Kelsall HL, Sim MR, Forbes AB et al. Symptoms and medical conditions in Australian veterans of the 1991 Gulf War: relation to immunisations and other Gulf War exposures. Occup Environ Med. 2005 Mar;62(3):142–3. "Increased symptom reporting was associated with several exposures, including having more than 10 immunisations, pyridostigmine bromide tablets, antibiological warfare tablets, pesticides, insect repellents, reportedly being in a chemical weapons area, and stressful military service experiences in a strong dose-response relation."

[89] Rose MR, Sharief MK, Priddin J et al. Evaluation of neuromuscular symptoms in UK Gulf War veterans: a controlled study. Neurology. 2004 Nov 9;63(9):1681–7.

[90] Wong R, Lopaschuk G, Zhu G et al. Skeletal muscle metabolism in the chronic fatigue syndrome. In vivo assessment by 31P nuclear magnetic resonance spectroscopy. Chest. 1992 Dec;102(6):1716–22.

13. ***Why have we no effective treatment strategies 16 years after the end of the war?***

VA Treatment Trials[91,92]

- The original two VA treatment trials were exorbitantly expensive, particularly given the number of subjects and cost of the interventions. Failure to conduct additional treatment studies was rationalized by these trials' high cost.
- The mycoplasma/doxycycline trial was a "failed study" in that positive results seen at 3 and 6 months did not carryover to 9- and 12-month followup, possibly due to a high dropout rate.[93] Yet it was not repeated with a larger number of veterans to reach a definitive conclusion regarding the benefit of antibiotic treatment.
- The cognitive behavioral therapy/exercise trial showed extremely modest gains and a high dropout rate; these treatments are known to be of little value in patients with chronic fatigue syndrome, and exercise can make them worse; yet cognitive behavioral therapy and exercise are primary treatments recommended for GW veterans, who have a high rate of chronic fatigue syndrome.

***We do not need to continue to examine whether the noxious exposures already studied can cause GWI. They can, and they did. And we should have expected it.** Some people were genetically more susceptible; some people received more or larger exposures. The result is that many veterans became chronically ill.

The manner in which DOD and VA pursued GW research was flawed for a variety of reasons.

- A significant amount of research focused on stress or psychiatric causes of illness.
- Certain exposures were studiously avoided as objects of study.
- Methodologies chosen were sometimes inadequate to answer the questions posed.
- Exposure data provided by DOD to researchers was not necessarily accurate.
- Funded studies were not selected on the basis of whether they would lead to a treatment, or to a policy change to protect future soldiers. Instead, some might suspect the research was designed to avoid uncovering negative information regarding use of DU, pyridostigmine bromide and anthrax vaccine.

This review of some GWI research shows that completed research projects have:

- confirmed the symptoms of the illnesses
- identified specific neurological deficits in affected veterans and some of their anatomic/physiologic correlates,
- provided partial information on rates of different GW-associated illnesses, and
- furthered our knowledge of the adverse effects caused by some noxious GW exposures, alone and in combination.

14. ***Where should the research go from here? How can we meld our research goals with the need to develop effective treatment strategies?***

Infections (where a treatment payoff could be very large)

- Perform conclusive research to determine if GW veterans have untreated chronic infections. Utilize all modalities including microscopy, specialized cultures, serology, PCR, etc. Develop new diagnostics when needed, such as for visceral leishmaniasis.
- Also seek novel infections (biological agents), using above techniques, genetic techniques, monoclonal antibodies, etc.
- Perform empiric antibiotic trials in veterans who test positive, including a repeat trial of antibiotics for veterans with positive mycoplasma forensic PCR (the test used to screen veterans for the earlier trial).

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[91] Donta ST, Clauw DJ, Engel CC Jr et al. Cognitive behavioral therapy and aerobic exercise for Gulf War veterans' illnesses: a randomized controlled trial. JAMA. 2003 Mar 19;289(11):1396–404.

[92] Donta ST, Engel CC Jr, Collins JF et al. Benefits and harms of doxycycline treatment for Gulf War veterans' illnesses: a randomized, double-blind, placebo-controlled trial. Ann Intern Med. 2004 Jul 20;141(2):85–94.

[93] Personal communication with Sam Donta, MD, the Principal Investigator.

Value for money

- A large number of small, inexpensive pilot studies should be funded instead of a few large, mainly epidemiologic studies; later give larger grants to those projects that show the most promise in terms of treatment strategies.
- Make the grant application process inclusive. Encourage clinicians who have been caring for GW veterans to participate. Reduce the complexity, time and cost needed to complete grant applications. Don't restrict VA research grants to VA employees, as has been the case: open the process to the best scientists and proposals.
- Note the low cost, excellent methodology, analysis and results of Lea Steele's Kansas veterans study,[94] compared to numerous Federally funded studies that cost at least ten times more and yielded much less information. Use her strategies as a model for other studies: passion for the subject, careful use of funds, thoughtful design and analysis.
- The selection process for grants must be transparent, which has not previously been the case.

Promising areas-basic research

The underlying causes of all the multi-symptom syndromes remain unknown. It is very probable that the molecular and cellular origin of these syndromes will be the same, although they are likely triggered by a variety of noxious exposures combined with genetic susceptibility. Because together these syndromes affect an estimated 6 million Americans, research identifying their underlying causes will pay enormous dividends, and should point the way to more effective treatment and prevention strategies.

- Gene expression studies have the potential to identify fundamental physiological processes that have been altered.[95,96,97] Genetic and proteomic studies of both predisposing gene patterns and protein differences between affected and unaffected veterans have already shown promise in pilot studies,[98,99] and should be continued.
- Abnormal ion channel function may provide a conceptual and physiologic bridge between fatigue, neuropathies and motor neuron disorders like ALS, providing clues to why different disorders develop after similar exposures.[100,101] It may also help explain episodic alterations in mental status, arrhythmias and epileptic seizures in veterans. Maintaining ion gradients across membranes requires a lot of cellular energy. This can potentially be improved with supplements that improve intracellular adenosine triphosphate (ATP) production and oral electrolytes.

Specific studies that could reap valuable rewards

- Detailed study of individual families, in which family members have developed illnesses similar to the ill veteran. An exhaustive search for microorganisms should be undertaken. Search for DU that may have been present on items that returned home with the veteran. Seek other toxics in the home as appropriate to illnesses. Investigate gene expression in these families.
- Study illnesses and mortality in selected units that have reported high death rates; try to recapture their locations, job descriptions and exposures when deployed.

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[94] Steele L. Prevalence and patterns of Gulf War illness in Kansas veterans: association of symptoms with characteristics of person, place, and time of military service. Am J Epidemiol. 2000 Nov 15;152(10):992–1002.

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[96] Fang H, Xie Q, Boneva R, Fostel J, Perkins R, Tong W. Gene expression profile exploration of a large dataset on chronic fatigue syndrome. Pharmacogenomics 2006 Apr;7(3):429–40.

[97] Whistler T, Jones JF, Unger ER et al. Exercise responsive genes measured in peripheral blood of women with chronic fatigue syndrome and matched control subjects. BMC Physiol. 2005 Mar 24;5(1):5.

[98] Baraniuk JN, Casado B, Maibach H et al. A chronic fatigue syndrome-related proteome in human cerebrospinal fluid. BMC Neurol 2005; December 1: 5:22.

[99] Vladutiu GD and Natelson BH. Association of medically unexplained fatigue with ACE insertion/deletion polymorphisms in Gulf War veterans. Muscle Nerve 2004; 30: 38–43.

[100] Kuwabara S, Misawa S. Axonal ionic pathophysiology in human peripheral neuropathy and motor neuron disease. Curr Neurovasc Res. 2004 Oct;1(4):373–9.

[101] Chaudhuri A, Watson WS, Pearn J, Behan PO. The symptoms of chronic fatigue syndrome are related to abnormal ion channel function. Med Hypotheses. 2000 Jan;54(1):59–63.

- Collect several hundred very ill GW veterans and perform exhaustive investigations on them, followed by treatment trials.
- Investigate those hypotheses for which researchers were threatened or forced to end their studies. Investigate the electromagnetic field strengths and frequencies of all weapons, communications devices and other equipment that may have been used in the war, and try to determine which areas or units were exposed and estimate the magnitude of exposure.
- The choice of control groups in research is critical to a meaningful outcome: compare GW veterans with controls who did not receive deployment vaccines and had demonstrated equivalent health status. Review all research projects with independent experts prior to funding, to minimize confounding and bias.
- Eight expert Committees have made recommendations on the research studies needed for anthrax vaccine since 1999.[102] Their recommendations are excellent, and should be followed.
- Eight hundred Israeli soldiers received U.S. anthrax vaccine or a similar Israeli anthrax vaccine several years ago, and dozens have reported chronic illnesses they believe are related to their vaccinations.[103] Information from this trial should be obtained, along with follow-up examinations to document what illnesses, if any, have developed and rates of illnesses.
- A clinical trial of various strategies to remove toxic substances would be extremely useful. Do antioxidants, vitamins, saunas, or other strategies safely remove toxins after an exposure and lead to better health?

Obtain relevant information from existing government databases

- The Army Medical Surveillance Activity has performed many analyses of its raw data (the Defense Medical Surveillance System) on the health status of soldiers and GW veterans. These studies were not published, nor are they easily available. A researcher[104] who filed Freedom of Information Act requests to learn what was studied, shared 66 pages with approximately 40 study titles listed per page with me. I have filed a Freedom of Information Act Request for the contents of 60 of these studies that pertain to the health of Gulf War veterans; my request is pending. Any serious study of Gulf War veteran health needs to make use of this material and the available military and VA databases. The Institute of Medicine noted that, "Analysis of DMSS data should be the primary approach for investigation of possible AVA (anthrax vaccine adsorbed)-related health effects of medical significance."[105] This should be true of other potential health impacts, in addition to anthrax vaccine.
- VA and military databases, used correctly, can tell us which other illnesses can be linked to the Gulf deployment, and the strength of the association, so that appropriate presumptions can be made about the illnesses' cause; disability decisions can then be made based on presumption.
- Independent researchers who gain access to this data to study GWI, and determine what other illnesses may be linked with the 1991 Gulf War deployment, should not be subject to the military chain of command nor be VA employees.
- We can learn more about the health risks of toxic GW exposures by gaining access to data held by Federal agencies. This includes obtaining information about anthrax vaccine adverse effects from FDA. What in-house studies or reviews have been done of anthrax vaccine? How has FDA evaluated the 5600 adverse event reports, particularly the 670 it judged serious? What assessment was done of the 44 reported deaths associated with anthrax vaccine? How is the vaccine tested for safety? (I filed several FOIAs with FDA for this information since 2001. So far, 99% of what I requested was redacted, and much has never been provided in any form. Yet the material should not have been withheld according to FDA guidelines (21 CFR20.61 and 21CFR601.51.)
- EPA and NIEHS have information about pesticide, heavy metal and solvent health risks. DOE has information on the makeup and production of depleted uranium. These sources of information should be explored for their potential to shed more light on the specifics of the illnesses causes by these materials.
- Anthrax vaccine trials: NIH has data on human trials of failed anthrax vaccines and CDC has data on its own clinical trial of 1564 subjects who received anthrax vaccine since 2002. What adverse events occurred in these carefully stud-

[102] http://merylnass.googlepages.com/Selectedfindings.doc
[103] http://www.haaretz.com/hasen/spages/863699.html
[104] Michael Ravnitzky
[105] IOM Committee to Review the CDC Anthrax Vaccine Safety and Efficacy Program. An Assessment of the CDC Anthrax Vaccine Safety and Efficacy Research Program. 2003.

ied groups? What is the current health of the subjects? Late follow-up could be done on these subjects to evaluate for longer term adverse events.
- Multiple vaccines: Currently deploying soldiers are receiving multiple simultaneous vaccinations and should be studied.
- The military vaccine healthcare centers have data on over 2,000 soldiers who have become ill after anthrax vaccines. As well as documenting the illnesses in great detail, the centers have tried a variety of treatment regimens. Information on the illnesses and the effectiveness of the treatments is extremely relevant to GW veterans.

15. ***My medical approach to treatment***

GWS is one of medicine's poor stepchildren for many reasons. Patients with memory and concentration problems require a lot more time and understanding from both physicians and clinic staff, compared to other patients. They miss appointments, lose prescriptions, forget the instructions you gave them. They have an average of eight different problems to address at each visit. They often have emotional issues. They are at high risk of family breakdown and economic collapse. Standard medications don't alleviate their symptoms. Providers may not understand their illnesses nor the context in which they seek care. They may be suspected as having secondary gain (desiring a disability pension) as the driver for medical visits. Yet sometimes almost the only thing the physician can do for the GWI patient is to aid the disability process by keeping detailed notes.

This syndrome is not described in textbooks. Journal articles may list the symptoms, but fail to guide clinicians with information on effective treatments. If the clinician reads the GWI literature, she may come away confused as to whether there really is a medical illness, and whether she should transfer the patient to the psychiatric clinic.

There are no standard medical treatments for the chronic effects of exposure to pesticides, solvents, toxic materials in inhaled smoke, etc. A few doctors have experimented with various detoxification strategies,[106,107] and some alternative doctors use these treatments frequently, but they are not proven to be effective and are not eligible for third party reimbursement.

Medicine is a business. Third party payers use similar visit codes to reimburse physicians. Treating four patients in an hour pays much better than treating one. The maximal visit code pays for a 40 minute visit. Additional time spent with the patient will not be reimbursed. Extra time spent by office staff is not reimbursed. I am fortunate that as a salaried physician, my employer, Mount Desert Island Hospital, allows me to conduct a specialty clinic as a community service, even though I could bring in considerably more fees treating patients with standard illnesses during brief visits. Patients often travel long distances to see these doctors, who are few and far between. Thus they need long visits. Few GW veterans can afford to pay out of pocket for medical care, which is how most doctors who treat multi-symptom syndromes expect payment, because of the limitations placed on reimbursement by insurers.

Frankly, until the financial disincentive is changed, I doubt that treatment of GW veterans will improve greatly.

What do I actually do with patients? First, patients complete detailed questionnaires prior to their visit to help me determine which aspects of the illnesses are present in their case. Because I am familiar with the features of the multisymptom syndromes, I know what to look for, ask about, and can direct treatment to these aspects of the illness. For example:

- Are they sensitive to odors (especially diesel exhaust), fluorescent lights or foods?
- What happens when exposed to these things?
- Do they have intermittent episodes of confusion?
- Do they balance their own checkbook?
- How is their driving?
- How is their GI tract function?
- How do they sleep? Has their partner noticed pauses in breathing?
- Do they have chronic pain? Where? What exacerbates or relieves it?
- What kind of activity can they perform? For how long? What makes them stop?
- Do they have rashes?

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[106] Krop J. Chemical sensitivity after intoxication at work with solvents: response to sauna therapy. J Altern Complement Med. 1998 Spring;4(1):77–86.

[107] Kilburn KH, Warsaw RH, Shields MG. Neurobehavioral dysfunction in firemen exposed to polycholorinated biphenyls (PCBs): possible improvement after detoxification. Arch Environ Health. 1989 Nov-Dec;44(6):345–50.

- How is their breathing?
- How is their libido and sexual function?
- Is there mold, or are there other substances at home or elsewhere that increase symptoms?

If they have developed multiple chemical sensitivity (which seems to be present in about 40% of GWS patients), I help them identify the odors that provoke symptoms so they can avoid them. I prescribe elimination diets to identify foods that trigger symptoms. I order tests to rule out other causes of symptoms, such as muscle diseases, standard autoimmune conditions, thyroid disease, anemia, etc. I may order sleep studies. Some patients may get a muscle biopsy or other specialized tests. Stools are cultured and endoscopy performed when indicated.

I then address treatment for each symptom individually, since we cannot currently address underlying causes. However, I additionally try to optimize patients' overall metabolic function with diet, vitamins and supplements designed to increase cellular energy and provide substrates for important intracellular molecules such as NADH, glutathione, ATP. Antioxidants may also be helpful. Most veterans cannot afford this treatment, however. Vitamins and supplements are not covered by insurance, although they are usually much cheaper than prescription medications.

Hopefully, clinical trials will demonstrate whether these approaches improve health, and if so, perhaps the VA will make vitamins and supplements available to GW veterans.

I treat the sleep disorder, diarrhea, pain, low hormone levels, or whatever other symptoms are present. I try one treatment after another, since there are many adverse reactions to medications, and it is often difficult to predict which medicines are likely to be effective. Usually, you can improve sleep considerably, but energy only a little. You can improve pain. The diarrhea can resolve, though it may return later. Sometimes sex hormones improve sexual function, but often they do not. Thyroid hormone may provide a modest energy boost. Autonomic dysfunction may be treated with increased salt and water intake, drugs and/or hormones to raise blood pressure, and electrolytes. If you are very lucky, cognition may improve.

The doctor-patient relationship, and lifestyle coaching, may be equally as important as medications. Patients need to know you are their partner, not a representative of a system they fear is pitted against them. I warn them that marital difficulties should be expected. I prefer their partners to attend visits, and am happy to answer partners' questions. Treating psychological problems may be helpful, but veterans are sensitive that such treatment is a denial they have physical illness. I explain that they have real medical illness, and may give them an article or book on GWS that describes the resulting psychological and physical symptoms, to help them understand their disorder. I may refer to other therapists. I suggest that people with limited mental and physical energy reserve their most challenging tasks for when they feel most rested. I may advise them not to drive alone.

With this treatment, I estimate a veterans' overall function can improve 30–40% and sometimes more. But it is a piecemeal, palliative, symptom-based approach that does not provide a cure. It also requires highly intensive care. A list of many of the treatments I employ was provided to the VA Research Advisory Committee and listed on my website at: *http://www.anthraxvaccine.org/gulfwartreatment.htm.*

I greatly appreciate this opportunity to share my knowledge and opinions with the Committee.

I would also like to express my appreciation to Walter Schumm, PhD, Garth Nicolson, PhD, and affected Gulf War veterans Doug Rokke, PhD, Joyce Riley, RN and Kirt Love for sharing materials on GWS that were used in this presentation. My deepest thanks also to Lt. Col. John Richardson, retired Air Force GW veteran (still healthy), who has worked tirelessly to improve the condition of his fellow GW veterans and anthrax vaccine-injured soldiers.

Committee on Veterans' Affairs
Subcommittee on Health
August 2, 2007

James Binns
Chairman
Research Advisory Committee on Gulf War Veterans' Illnesses
U.S. Department of Veterans Affairs
2398 East Camelback Road, Suite 280
Phoenix, AZ 85016

Dear Jim:

In reference to our Subcommittee on Health hearing on "Gulf War Exposures" held on July 26, 2007, I would appreciate it if you could answer the enclosed hearing questions by the close of business on October 2, 2007.

In an effort to reduce printing costs, the Committee on Veterans' Affairs, in cooperation with the Joint Committee on Printing, is implementing some formatting changes for materials for all full and Subcommittee hearings. Therefore, we would appreciate it if you would provide your answers consecutively and single-spaced. In addition, please restate the question in its entirety before the answer.

Please provide your response to Cathy Wiblemo at the Committee. If you have any questions, please call 202–225–9154.

Sincerely,

MICHAEL H. MICHAUD
Chairman

Research Advisory Committee on Gulf War Veterans' Illnesses
U.S. Department of Veterans Affairs
Phoenix, AZ
October 2, 2007

Hon. Michael H. Michaud
Chairman
Subcommittee on Health
Committee on Veterans' Affairs
United States House of Representatives
335 Cannon House Office Building
Washington, DC 20515

Dear Congressman Michaud:

I am pleased to respond to your written questions following the July 26 hearing on "Gulf War Exposures."

1. *Gulf War Illnesses*—Everyone on this panel agrees that Gulf War Illnesses are real and that more should be done by way of research, outreach and treatment.

- In your professional estimation, what is the biggest challenge facing VA today with regard to Gulf War Illnesses?

In recent years, I have observed VA's Office of Research and Development change course to embrace the reality of these illnesses and redirect VA research to address the problem, thanks to the active leadership of Secretary Principi and Secretary Nicholson. Indeed VA research is responsible for much of the progress that has been made in understanding that these are widespread, serious health problems, neurological in nature, rather than the result of battlefield stress. Even since the July 26 hearing, Dr. Kupersmith, the head of research and development, has continued this advance by announcing new studies to investigate the prevalence of MS and brain cancer in Gulf War veterans.

Other parts of VA, however, notably the Office of Environmental Hazards, continue to push the old message that minimizes these illnesses and associates them with psychological causes, whether in "fact sheets" provided to Congress or outdated clinical training guidelines given to VA doctors. This activity misleads the scientific community that might be engaged in helping these veterans and denies VA the credit it should be receiving for addressing the problem head-on. In my estimation, the biggest challenge facing VA today with regard to Gulf War Illnesses is to project throughout the department the perspective of VA leadership and the Office of Research and Development.

Dr. Deyton, who was appointed the new head of the Office of Public Health and Environmental Hazards relatively recently, has a reputation as a straightforward and dedicated senior official. am hopeful that he will address this challenge.

- What would your recommendations be to VA to ensure that what has happened to Gulf War Veterans does not happen to the newest generation of veterans returning from OEF/OIF?

Our Committee submitted a list of recommendations to Deputy Secretary McKay before the start of the war in Iraq, a copy of which is attached, and which formed the basis of a letter from VA leadership to the Department of Defense.

2. *DoD/VA*—Getting accurate, up-to-date information on pre-deployment and post-deployment health records, where service members were located and other pertinent information from DoD, has, in the past, been characterized as difficult.

- Do you believe that this exchange of information between VA and DoD has improved with the current deployments to Afghanistan and Iraq?

As the current war is outside the charter of the Research Advisory Committee, I regret that I have no personal knowledge to offer.

- In your professional opinion, would you say that the lack of information exchange or delayed exchange was a primary factor in hindering research efforts regarding Gulf War Illnesses?

It has been a factor that has hindered research.

3. *ALS*—Mr. Mikolajcik proposed in his testimony that a congressionally directed ALS Task Force should be established to help provide direction in ALS research and to develop a strategic plan to tackle this illness. The 30- 60- 90-day timeline he suggested in his testimony lays out some structural parameters.

- What are your thoughts on creating another task force or entity to look into ALS?
- Do you believe that the direction VA is taking with ALS is the right way?

Other than the research studies specifically directed at Gulf War veterans with ALS, our Committee is not charged with reviewing ALS research and has not reviewed the VA ALS portfolio. Thus I regret that I am unable to comment knowledgeably on this question. Coming from private industry, my general impression of government and academic research programs is that many would benefit from a more comprehensive, integrated approach. In my opinion, a task force would need to consider the full scope of ALS research, not only VA, to be effective, and I would want to know if some entity (such as at NIH?) already has that responsibility and if they were executing it effectively.

4. *Where Do We Go From Here*—Sixteen years have passed and veterans of the Gulf War are still fighting to be recognized and not forgotten.

- What would your recommendations be on how to effectively move forward with Gulf War illnesses research, outreach, education and treatment?

The Research Advisory Committee is currently preparing a comprehensive report that will address these topics in detail. I look forward to providing it to you as soon as it is available, early in the new year. Certain of these topics that have already been addressed by the Committee are available now at the Committee website: http://www1.va.gov/racgwvi/docs/Letter_Recommendations_Feb012007.pdf

Respectfully submitted,

James Binns
Chairman

Research Advisory Committee on Gulf War Veterans' Illnesses
U.S. Department of Veterans Affairs
Phoenix, AZ
December 16, 2002

Hon. Leo S. Mackay, Jr., PhD
Deputy Secretary of Veterans Affairs
Department of Veterans Affairs
Washington, DC

RE: "Lessons Learned"

Dear Mr. Deputy Secretary,

At the recent meeting of the Research Advisory Committee on Gulf War Veterans Illnesses, you asked if the Committee had recommendations regarding the prospective conflict with Iraq based on lessons learned from the Gulf War Illnesses experience.

Because the request came at the end of our meeting, these observations did not in all cases go through the formal process for recommendations of a public advisory committee and they are not comprehensive. However, we appreciate your interest, and offer these observations for consideration as time is of the essence.

1. DoD should retain health and locational records for future conflicts. Even if security considerations require classification of personnel records, they should be retained for health reasons.
2. Predeployment physicals should be standardized.
3. Military exit physical examinations should be conducted in accordance with procedures that meet VA standards.
4. There should be a single comprehensive DoD/VA patient record.
5. Good immunization records should be maintained.
6. [The following recommendation was formally deliberated and adopted by the Committee.]
   "Substantial questions remain about the possible contribution of vaccines, including the anthrax vaccine, to chronic ill health experienced by veterans of the 1991 Gulf War. Evaluation of the contribution of vaccines in the 1991 conflict would have been aided by proper and extant vaccination records including specifics of vaccine lots received and dosage schedules. Should such health problems recur after future deployments or after civilian vaccination programs, VA's ability to evaluate and treat affected veterans would require access to comprehensive vaccination records. To fill this gap of knowledge we recommend that stringent efforts be made to generate and keep such records and to perform active surveillance of both short term and long term adverse health effects of all biodefense vaccines, including the anthrax vaccine. We therefore recommend to the Secretary of Veterans Affairs that he initiate discussions with the Secretary of Defense to ensure that this is achieved."
7. Several members of the Committee pointed out that most of these recommendations were enacted into law in the Force Health Protection statute, PL 105–85. They report, however, that a recent GAO study and Congressional hearings indicate that compliance with this law is weak at the operational unit level. Thus, a core recommendation would be to encourage you and Secretary Principi to work with your counterparts at the Department of Defense to ensure that these laws are implemented.

Respectfully submitted,

James H. Binns
Chair

cc: Hon. Anthony J. Principi,
Secretary of Veterans Affairs

Committee on Veterans' Affairs
Subcommittee on Health
August 2, 2007

Lea Steele, Ph.D.
Scientific Director
Research Advisory Committee on Gulf War Veterans' Illnesses
Eastern Kansas VA Healthcare System (T–GW)
2200 S.W. Gage Blvd.
Topeka, KS 66622

Dear Lea:

In reference to our Subcommittee on Health hearing on "Gulf War Exposures" held on July 26, 2007, I would appreciate it if you could answer the enclosed hearing questions by the close of business on October 2, 2007.

In an effort to reduce printing costs, the Committee on Veterans' Affairs, in cooperation with the Joint Committee on Printing, is implementing some formatting changes for materials for all full and Subcommittee hearings. Therefore, we would appreciate it if you would provide your answers consecutively and single-spaced. In addition, please restate the question in its entirety before the answer.

Please provide your response to Cathy Wiblemo at the Committee. If you have any questions, please call 202–225–9154.

Sincerely,

MICHAEL H. MICHAUD
Chairman

Questions for the Record
Hon. Michael H. Michaud, Chairman
Subcommittee on Health
House Committee on Veterans' Affairs
July 26, 2007, 10:00 a.m.
Room 334, Cannon House Office Building

Follow-Up Questions for Lea Steele, Ph.D.

1. ***Gulf War Illnesses*****—**Everyone on this panel agrees that Gulf War Illnesses are real and that more should be done by way of research, outreach and treatment.

- In your professional estimations, what is the biggest challenge facing VA today with regard to Gulf War Illnesses?
- What would your recommendations be to VA to ensure that what has happened to the Gulf War Veterans does not happen to the newest generation of veterans returning from OEF/OIF?

2. ***DoD/VA*****—**Getting accurate, up-to-date information on pre-deployment and post-deployment health records, where service members were located and other pertinent information from DoD, has, in the past, been characterized as difficult.

- Do you believe that this exchange of information between VA and DoD has improved with the current deployments to Afghanistan and Iraq?
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3. ***ALS*****—**Mr. Mikolajcik proposed in his testimony that a congressionally directed ALS Task Force should be established to help provide direction in ALS research and to develop a strategic plan to tackle this illness. The 30- 60- 90-day timeline he suggested in his testimony lays out some structural parameters.

- What are your thoughts on creating another task force or entity to look into ALS?
- Do you believe that the direction VA is taking with ALS is the right way?

4. ***Where Do We Go From Here*****—**Sixteen years have passed and veterans of the Gulf War are still fighting to be recognized and not forgotten.

- What would your recommendations be on how to effectively move forward with Gulf War Illnesses research, outreach, education and treatment?

[RESPONSES WERE NOT RECEIVED FROM DR. STEELE.]

Committee on Veterans' Affairs
Subcommittee on Health
August 2, 2007

Lawrence Deyton, MSPH, M.D.
Chief Public Health and Environmental Hazards Officer
Office of Public Health and Environmental Hazards
U.S. Department of Veterans Affairs
810 Vermont Avenue, NW
Washington DC 20420

Dear Lawrence:

In reference to our Subcommittee on Health hearing on "Gulf War Exposures" held on July 26, 2007, I would appreciate it if you could answer the enclosed hearing questions by the close of business on October 2, 2007.

In an effort to reduce printing costs, the Committee on Veterans' Affairs, in cooperation with the Joint Committee on Printing, is implementing some formatting

changes for materials for all full and Subcommittee hearings. Therefore, we would appreciate it if you would provide your answers consecutively and single-spaced. In addition, please restate the question in its entirety before the answer.

Please provide your response to Cathy Wiblemo at the Committee. If you have any questions, please call 202–225–9154.

Sincerely,

MICHAEL H. MICHAUD
Chairman

Questions for the Record
Hon. Michael H. Michaud, Chairman
Subcommittee on Health
House Committee on Veterans' Affairs
July 26, 2007

Gulf War Exposures

Question 1: ***Outreach*****—**The Gulf War Review newsletter, which is the publication VA initiated to help veterans of the Gulf War and their families be more aware of VA's health care and other benefits has reportedly not been mailed out in over a year.

- What has the VA done to ensure that outreach to Gulf War veterans is being done on a regular basis?

Response: The Department of Veterans Affairs (VA) places a very high priority on ensuring broad and wide-ranging outreach to all veterans, including veterans of the Gulf War.

To achieve this, VA has a great deal of material made available to Gulf War veterans and their families, including information newsletters, brochures, wallet cards, posters, and other materials, both in print, online and as "pod casts," to ensure that veterans and their families are kept up to date on the VA health care and other benefits that may affect them.

Some VA outreach materials specifically targeting veterans of the 1991 Gulf War[1] and their families available online at www.va.gov/GulfWar and www.va.gov/EnvironAgents (see summary of this outreach information, Attachment 1).

Since 1992, VA has published 38 editions of the "Gulf War Review" newsletter. The next edition will appear in the Fall of 2007. That edition will highlight a number of new authoritative reports from the independent National Academy of Sciences Institute of Medicine (IOM) which will be completed by then, and should be of significant interest to Gulf War veterans and their families.

Question 2: ***Treatment*****—**Because they suffer from a multitude of illnesses, the treatment of Gulf War veterans is by most counts, pretty complex. Additionally, Anthony Hardie, in his testimony states that the VA's Office of Public Health and Environmental Hazards website contains little information that might be of any use to ill Gulf War veterans or their health providers.

- Could you tell us what type of training or continuing medical education requirements are currently in place to ensure that VA health care professionals have the most current research findings and up-to-date information on the Gulf War Illnesses?

Response: VA has a wide range of training and educational materials on Gulf War veteran health issues, aimed at VA health care providers as well as for veterans and their families.

Attached is a brief description of some VHA initiatives from the Office of Public Health' and Environmental Hazards (OPHEH), developed for training and education purposes for VA health care providers seeing Gulf War 1 veteran patients (Attachment 2).

Many of these programs have now also been expanded to prepare for veterans from Operations Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) and for their families. All of these programs represent "lessons learned" from VA's experiences responding to the health care and other benefits needs of veterans returning from the 1991 Gulf War, and from the Vietnam War before that.

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[1] (Note: In the responses the 1990–1991 Gulf War is sometimes referred to as Gulf War 1.)

The most authoritative sources of health information for veterans of the 1991 Gulf War is the series of congressionally mandated "Gulf War and Health" reports conducted by the IOM. These reports have reviewed a wide range of Gulf War risk factors, including health effects from exposure to oil well fire smoke. Summaries of these reports are available online at www.va.gov/EnvironAgents for the benefit of both veterans and VA health care providers.

In addition, VA's Office of Research and Development (ORD) disseminates an annual report, written jointly with the Departments of Defense (DoD) and Health and Human Services (HHS), which summarizes Federally supported research on Gulf War veterans' health available online at http://www.research.va.gov/resources/pubs/pubs_individual.cfm?Category=Gulf War Reports.

Question 3: ***Epidemiological Research*****—**On page 3 of your testimony you say "additional epidemiological research is required to properly characterize any possible long-term health effects of Gulf War One service to the average Gulf War veterans.

- Has VA initiated the needed research and if not, why not?

Response: An enormous amount of epidemiological research has been carried out focusing on the health of veterans of the 1991 Gulf War. Some of this research has been supported or conducted by VA researchers, but most of it has been conducted by a wide range of academic and government researchers around the world.

The quoted reference in VA's testimony was making the point that VA's Gulf War Health Registry program was not intended for definitive evaluation of specific health effects for the average Gulf War veteran. To do that thoroughly requires epidemiological research to fully characterize any possible long-term health effects of Gulf War 1 service. Gulf War Health Registry participants are self-selected, and therefore do not represent the average veteran. Registry findings do show that no unique health problems are emerging among those Gulf War veterans who have participated in the special registry program. However, these findings do not tell us if Gulf War veterans are suffering from any diagnoses at rates different from that expected among this group, based on their age and demographic characteristics.

To gain an overview about how this enormous effort has improved our understanding of Gulf War veteran health issues, in 2004, VA requested an in depth review by the National Academies of Sciences IOM, of all epidemiological studies of Gulf War veterans. This was the fourth in a series of statutorily required (in Public Laws 105–277 and 105–368) studies by the IOM on the scientific and medical literature on the long-term health effects from exposure to a wide range of environmental hazards potentially related to service in the 1991 Gulf War. The 2004 IOM Committee was charged with reviewing all epidemiological studies of health outcomes among Gulf War veterans to determine their health status in comparison with other populations.

The resulting 2006 IOM Committee report documented increased rates of certain illnesses among Gulf War veterans, based on a review of 850 epidemiological and other studies of this group, which they selected from among over 4,DoD potentially relevant reports. The IOM Committee concluded:

"VA and DoD have expended enormous effort and resources in attempts to address the numerous health issues related to the Gulf War veterans. The information obtained from those efforts, however, has not been sufficient to determine conclusively the origins, extent, and potential long-term implications of health problems potentially associated with veterans' participation in the Gulf War."

The IOM Committee identified numerous serious limitations in existing epidemiological studies of Gulf War veterans, in large part due to the lack of data on veterans' exposure to putative toxic agents. However, they did "not recommend that more such studies be undertaken for the Gulf War veterans." Rather, the Committee recommended "continued surveillance to determine whether there is actually a higher risk in Gulf War veterans" for illnesses that current research has identified as possibly appearing at higher rates among Gulf War veterans, specifically, brain and testicular cancer, amyotrophic lateral sclerosis (ALS), birth defects, and post deployment psychiatric conditions.

The IOM Committee concluded that "every study reviewed by this Committee found that veterans of the Gulf War report higher rates of nearly all symptoms examined than their non-deployed counterparts."

Of note, they reported that symptom-defined "unexplained illnesses," consistent with chronic fatigue syndrome, fibromyalgia, irritable bowel syndrome and multiple chemical sensitivity, were the most common health problem reported in studies of Gulf War veterans. However, they concluded that "the results of research indicate that although deployed veterans report more symptoms and more severe symptoms

than their non-deployed counterparts, there is not a unique symptom complex (or syndrome) in deployed Gulf War veterans." They also found that "Gulf War veterans consistently have.been found to suffer from a variety of psychiatric conditions," including post traumatic stress disorder (PTSD), anxiety, depression and substance abuse.

They also reported that studies have "not demonstrated differences in cognitive and motor measures" in deployed versus non-deployed veterans, and show no apparent increase in risk of peripheral neuropathy, cardiovascular disease or diabetes.

Finally, they reported difficulties in interpreting data on birth defects, and found little data to support an objective finding of increased respiratory illnesses among Gulf War veterans.

VA's Office of Research and Development also prepares an annual report on Federally sponsored research on Gulf War veterans' illnesses (their latest report is dated May 2007). Research topics have included large population-based epidemiological studies 1991 Gulf War veterans, including on symptoms and general health status, brain and nervous system function, diagnoses of infectious diseases, health effects of depleted uranium (DU), chemical weapons, and pyridostigmine bromide, and multiple exposure effects.

It is important to note that the U.S. government has provided significant support for research on the health of Gulf War veterans. From fiscal year (FY) 1992 through FY 2006, VA, DoD and HHS funded 330 distinct projects related to health problems affecting Gulf War veterans. These projects are broad in scope, from small pilot studies to large-scale epidemiology studies involving large populations and major center-based research programs. Federal funding for research on Gulf War veterans totaled $274.0 million over FY 1997 to FY 2006, and as of September 2006, 223 projects (68 percent) were completed, while 107 (34 percent) were new or ongoing.

VA's own research activities focusing on veterans of the 1991 Gulf War include:

1. A comprehensive mortality study, which continues even today;
2. An interagency study on veteran hospitalization rates;
3. VA's National Health Survey of Gulf War veterans and their families; and,
4. Surveillance on long-term health effects from exposure to DU among Gulf War veterans.

One example of VA research is a study of mortality and causes of mortality among all Gulf War veterans. For this effort, VA researchers have been continuously monitoring the cause-specific mortality of all Gulf War veterans in comparison to their non-deployed peers. In post-war monitoring, Gulf War veteran mortality from most causes is not significantly different in comparison to non-deployed peer as controls. Moreover, the mortality for both groups is less than half that of matched civilian controls. This is almost certainly because people who choose to go into the military are healthier to begin with.

Initially, Gulf War veterans have shown an increased risk of death from accidents, especially motor vehicle accidents. VA's data shows that this is a temporary effect, and by 6 years post-war this difference has disappeared. This overall pattern is very consistent with earlier mortality data from Vietnam veterans.

The Washington DC VA War-Related Illness and Injury Study Center (WRIISC) has also initiated significant research on the possible long-term health effects of the 1991 Gulf War service. These include:

1. Post War Mortality from Neurologic Diseases in Gulf War Veterans

The concept behind this study is that Gulf War veterans may be at increased risk for neurological disorders, amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), Parkinson's disease, or brain cancer, as a result of their Gulf War service. These risks are related to potentially hazardous environmental exposures during the war, such as oil well fire smoke, chemical and biological warfare (CBW) agents, prophylactic agents against CBW, multiple vaccinations, depleted uranium, pesticides, and endemic infectious diseases. Therefore, the Washington, DC-based WRIISC is investigating post-war mortality from neurological disease in Gulf War veterans. This study compares risks of mortality due to ALS, MS, Parkinson's, or brain cancer between 620,DoD Gulf War veterans and 750,DoD non-Gulf War veterans. The study is scheduled to be completed by the end of 2007.

2. Estimates of Cancer Prevalence in Gulf Veterans Using State Registries

For this study, WRIISC researchers are evaluating the hypothesis that 1990–1991 Gulf War veterans are at an increased risk of developing specific cancers compared to nonGulf War veterans. The objectives of the study are (a) to assess and compare the prevalence, distribution, and characteristics of cancer among 621,902 Gulf War veterans to 746,248 non-Gulf War veterans; and (b) to assess demographic, military,

and in-theater exposure characteristics associated with the cancer. They are identifying Gulf War and non-Gulf War veterans with a diagnosis of cancer from 1991 to 2005 through record linkage of the veterans' database with files supplied by state cancer registries. This study will produce information with adequate statistical power to address the question on whether or not there is an excess cancer risk associated with the 1990–1991 Gulf War. The study is scheduled to be completed by the end of 2008.

3. Autonomic Functions of Gulf War Veterans with Unexplained Illnesses

This population-based, clinical pilot study is designed to measure and compare functions of the autonomic nervous system in Gulf War 1 veterans who have a cluster of neurological symptoms to Gulf War 1 veterans without these symptoms. Researchers will explore two questions: first, is autonomic nervous system function impaired in Gulf War veterans with a cluster of neurological symptoms (e.g., dizziness, blurred vision, tremor, and excessive fatigue) compared to those without; second, are these symptoms associated with abnormal testing for specific functions of the autonomic nervous system. The study is scheduled to be completed in 2 years.

4. Motor Neuron Function of Gulf War Veterans with Excessive Fatigue

This pilot study is designed to explore whether the number of motor neurons is significantly reduced in ill Gulf War 1 veterans compared to controls; and if mitochondrial (energy producing cells) function is impaired in ill Gulf War One veterans compared to controls. III veterans will have at least one of the following self-reported neuromuscular symptoms: muscle weakness, muscle pain or cramp, excessive fatigue, recurring fatigue lasting more than 24 hours after exertion, or having chronic fatigue syndrome. The study is scheduled to be completed in 2 years.

Question 4: ***WRIISCs*****—**In 2001, VA established the War Related Illness and Injury Study Centers (WRIISCs), at the Washington, D.C, and East Orange, NJ VA Medical Centers. The centers were established initially for returning 1991 Gulf War veterans however the centers see combat veterans from all deployments. It is good to see that VA is expanding on this program and establishing a third WRIISC at the Palo Alto VA Health Care System.

Response: In 2001, as part of VA's overall health response for veterans returning from the 1991 Gulf War, VA established the two WRIISCs at Washington, DC, and East Orange, NJ. Today, they are providing specialized health care for combat veterans from all deployments who experience difficult to diagnose.or undiagnosed but disabling illnesses.

Currently, VA is expanding this program to better meet the health care needs of new combat veterans suffering from mild to moderate traumatic brain injury. To that end, VA is establishing a third WRIISC at the Palo Alto VA Health Care System, in Palo Alto, CA.

Question 4(a): How many Gulf War One veterans are seen at the two centers?

Response: The two existing WRIISCs, established in 2001, have evaluated 344 Gulf War veteran patients from across the nation.

Question 4(b): Have there been any significant findings or recommendations that have emanated from the study centers since opening in 2001?

Response: The two WRIISCs were charged with developing new approaches for responding to all veterans with disabling but difficult or impossible to diagnose illnesses. They were required to focus on 1) specialized clinical care; 2) research on improved diagnoses and treatments; 3) relevant education for health care providers; and 4) risk communication and outreach for veterans and their families with deployment-related health concerns.

The two WRIISCs have achieved a great deal in each of these four core areas, and we have attached their latest annual reports to provide more complete information about their accomplishments. (Attachment 3)

Question 4(c): Do you know how many OEF/OIF veterans have been seen at the centers?

Response: The WRIISC program has evaluated 577 OEF/OIF veterans, beginning in 2005.

Question 4(d): What types of unexplained disabling illnesses or difficult to diagnose illnesses are OEF/OIF veterans experiencing?

Response: OEF/OIF veterans present to the two WRIISCs with musculoskeletal injuries and related pain, dental conditions, PTSD, mood disorders, and traumatic brain injury (TBI). WRIISCs report that they generally consider mild TBI as difficult to diagnose among returning OEF/OIF veterans, especially when, as is commonly the case, their symptoms are complicated with overlapping PTSD and other

mental health conditions. Clearly, mild TBI was not a significant concern as a consequence of the 1991 Gulf War, but certainly is one for the current conflict in Southwest Asia. We are expecting these clinical findings to appear in future publications from the two WRIISCs.

Many of the long-term chronic health effects from TBI appear similar to the difficult-to-diagnose and treat illnesses currently being treated by the WRIISC programs today. To improve our ability to respond to the health care needs of combat veterans suffering from mild to moderate TBI, VA is establishing a third WRIISC at the Palo Alto VA Health Care System. The new WRIISC will take advantage of the unique assets available there, including a poly trauma unit, interdisciplinary program on blast injuries which integrates the medical, psychological, rehabilitation, prosthetic needs of injured service members, their programs in TBI, spinal cord injury, blind rehabilitation, PTSD, and research into new and emerging areas of combat injuries and illnesses.

Finally, WRIISC have reported that sleep disturbances are rather common finding among new OEF/OIF veterans. This is a difficult symptom because it is sometimes hard to pinpoint their underlying cause. Commonly, OEF/OIF veterans' circadian rhythm appears to be disrupted as a result of irregular sleeping patterns in theater, but often this issue is compounded by PTSD.

Question 4(e): Are the OEF/OIF veterans experiencing different maladies than those presented by the Gulf War One veterans?

Response: The WRIISCs report that based on recent clinical experience with these new veterans that in general, health issues among OEF/OIF veterans have many similarities as well as certain differences compared to veterans of the 1991 Gulf War. They report that there appear to be more exposure-related illness concerns among Gulf War 1 veterans, for example, related to oil well fires, chemical weapons potential, and vaccinations. OEF/OIF veterans also have some concerns about these deployment-related concerns, including relative to vaccinations, depleted uranium, and air quality issues. Symptoms and illnesses vary depending on the conflict in which the veteran served. However, symptoms related to depression, PTSD, pain, memory difficulties, respiratory, and skin conditions are common among new combat veterans.

Significant post-deployment health concerns of Gulf War 1 veterans are medically unexplained symptoms, including headaches, fatigue, gastrointestinal disturbances, chronic pain, memory difficulties, and mood disorders. Gulf War 1 veterans also see Gulf War environmental exposures as the etiology for their health symptoms. The deployment health concerns of OEF/OIF veterans include musculoskeletal injuries and related pain, dental conditions, PTSO, mood disorders and TBI.

Question 5: ***ALS Research*****—**You mention in your testimony that there is ongoing research being done by VA regarding ALS.

Do you know when the results of some of this research will be complete or are these studies that will take years to come to fruition?

Response: Most of the research studies on ALS funded by ORD are long-term research projects that will take some years to come to fruition. Projects aimed at identifying genetic markers for ALS are closer to providing useful tools for clinicians to diagnose ALS and potentially to follow disease progression, however, there is no definitive timeframe for completion of these studies. The ORD-sponsored VA National ALS Registry is currently being used by investigators funded by a broad spectrum of agencies, including VA and DoD.

Question 6: ***ALS Registry*****—**There is a national registry of veterans with ALS to identify, as completely as possible, all veterans with ALS and to collect data for studies examining the causes of ALS.

Question 6(a): How many veterans are currently on the registry?

Response: Since 2003, VA has enrolled a total 2027 veterans. Currently, 965 of these veterans are alive and engaged in biannual follow-up.

Question 6(b): Do you have any veterans from the current conflict on the registry?

Response: There are 10 veterans from OEF and 3 from OIF enrolled.

Question 6(c): How do you reach out to veterans to make them aware that the registry exists?

Response: VA makes veterans aware that the registry exists through a variety of mechanisms including:

- The ALS Registry website (http://www.durham.hsrd.research.va.gov/alsreqistrv.asp)

- Letters and brochures sent to all neurologists (VA and non-VA)
- Announcements on ALS and veteran-specific websites

Brochures sent to national and state ALS Associations

Periodic data-pulls from VA Inpatient/Outpatient databases followed by a contact letter to veterans and a call 1 week later to determine eligibility

Question 6(d): Have you tried to specifically target veterans from the first Gulf War given that they are twice as likely to contract ALS?

Response: All veterans in the VA funded study, "An Investigation into the Occurrence of ALS Among Gulf War Veterans" were contacted and enrolled in the ALS Registry. In addition, VA contacted the Persian Gulf War Veterans Association and requested that it notify veterans about the registry.

Attachment 1

Partial list of Outreach Materials for Gulf War veterans and their families available online at www.va.gov/GulfWar. www.va.gov/EnvironAgents and other sources.

At the www.va.gov/GulfWar Web site, Gulf War veterans and their families have access to:

- VA's Gulf War Veterans Information Helpline (1–800–PGW-VETS)
- The most recent VA Gulf War Newsletter (July 2006)
- VA's Gulf War (OIF) Registry Program Handbook (June 2007)
- The Annual Report to Congress on Gulf War Veterans' Illnesses from VA/DoD Research Working Group
- Veterans Health Initiative (VHI) Independent Study Guide for Providers on Gulf War Health Issues
- VA's Depleted Uranium Handbook for Gulf War Veterans (February 2004)
- VA's Evaluation Protocol for Gulf War OIF Veterans with Potential Exposure to Depleted Uranium (DU) Handbook
- VA's Southwest Asia Poster (May 2004) (distributed to all VA medical centers, regional offices and vet centers)

Brochures and Information Bulletins:

- Health Care and Assistance for U.S. Veterans of OIF
- Q&A Brochure—Gulf War Illnesses, August 2003 (English and Spanish)
- Information Bulletin on Gulf War veteran health issues 10–41 and—42, March 2004 (in Spanish)
- Gulf War Fact Sheet April 2 DoD
- Depleted Uranium Frequently Asked Questions (FAQs)
- VA Gulf War Registry Examination Handbook 2005

Research Reports and Summaries:

- Combined Analysis of VA/DoD Gulf War Clinical Evaluation Programs (Study of Clinical Findings from Systematic Medical Examinations of 100,339 U.S. Gulf War Veterans)—September 2002
- Gulf War Research: A Report to Veterans October 2003 (English and Spanish)
- Journal Article Summaries on Gulf War veteran health issues
- Gulf LINK Medical Information (Gulf LINK is DoD's site on Gulf War veteran health issues containing Gulf-War research-related information. It is a collaborative effort of DoD, VA, and HHS.

Gulf War Risk Factor Report Reprints (from VA's "Gulf War Review" Newsletter):

- Introduction
- Deplete Uranium
- Pesticides
- Pyridostigmine Bromide
- Infectious Diseases
- Chemical & Biological Warfare Agents
- Vaccinations including Anthrax & Botulinum
- Oil Well Fire Smoke and Petroleum

At the www.va.gov/EnvironAgents Web site, Gulf War veterans and their families have access to a wide range of information on health and other information that may affect them, including:

Brochures:

- Depleted Uranium & Health Pocket Guide For Clinicians (May 2007)

- Special Health Registry Examination Programs (including the Gulf War Health Examination Registry Program) (June 2006)
- Your Story: Tell Your Military History (November 2005)

Fact Sheets:

- OIF Veterans: Information For Veterans Who Served In Iraq In 2003–04 and Beyond and Their Families (IB 10–166) December 2004
- OEF Veterans: Information For Veterans Who Served In Afghanistan and Their Families (IB 10–71) December 2004
- Ionizing Radiation Brief: Fact Sheets For Those Concerned About Possible Long-Term Health Consequences of Ionizing Radiation Exposure (December 2004)

Newsletters:

- OEF/OIF Review: Information for Veterans Who Served In Afghanistan and Iraq and Their Families (July 2007)
- OEF/OIF Review: Information for Veterans Who Served In Afghanistan and Iraq and Their Families (April 2007)

Pod Casts (downloadable audio files for veterans):

- Polytrauma Centers (April 2007)
- Blast Injuries (April 2007)
- Transition Assistance Advisors (April 2007)
- New Brochure Explains Registry Programs (April 2007)
- Newsletter Editor Rosenblum Retires (April 2007)
- Readjustment After Deployment (April 2007)
- How To Apply For Disability Compensation From VA (April 2007)
- En Español: Cómo aplicar para la compensación de incapacidad en el VA (Abril 2007)
- Special Compensation (April 2007)
- Quick Guide To Traumatic Brain Injury (April 2007)
- WRIISC: National Referral Program (April 2007)
- WRIISC: Transition and Orientation Class (April 2007)

Under Secretary for Health Information Letters (IL):

- Under Secretary for Health's IL 10–2006–010: Potential Health Effects Among Veterans Involved In Military Chemical Warfare Agent Experiments Conducted From 1955 to 1975 (August 14, 2006)
- Chemical Warfare Agent Experiments among U.S. Service Members (Updated August 2006)
- VBA Letter and DoD Fact Sheet and FAQs For Veterans Involved in Military Experiments at Edgewood/Aberdeen with Chemical Warfare Agents from 1955 to 1975 (June 30, 2006)
- Under Secretary for Health's Information Letter (IL 10–2006–004): Screening and Clinical Management of Traumatic Brain Injury (January 25, 2006)
- Under Secretary For Health's Information Letter (IL 10–2005–020): New Study Reporting Increased Risk Of Brain Cancer Deaths Among 1991 Gulf War Veterans Possibly Exposed To Sarin Chemical Warfare Agent At Khamisiyah, Iraq (September 15, 2005)
- DoD Letter, Fact Sheet and FAQs for Gulf War Veterans Who Served Near Khamisiyah, Iraq (September 27, 2005)
- Under Secretary for Health's Information Letter (IL 10–2005–004): Health Effects among Veterans Exposed To Mustard Gas And Lewisite Chemical Warfare Agents (March 14,2005)
- Under Secretary for Health's Information Letter (IL 10–2004–013): Guidance For The Diagnosis And Treatment Of Leishmania Infection (October 6,2004)
- Under Secretary for Health's Information Letter (IL 10–2004–007): Possible Long-Term Health Effects from The Malarial Prophylaxis Mefloquine (Lariam) June 23, 2004
- Undersecretary for Health's Information Letter (IL 10–2003–014): Long-Term Effects of Heat-Related Illnesses (November 20, 2003)

Veterans Health Administration Directives:

- VHA Directive (2005–020)—Determining Combat Veteran Eligibility (June 2, 2005)

Veterans Health Administration Handbook—VA Health Care, Benefits and Eligibility Information for Veterans:

- VHA Handbook 1303.2, Gulf War (Including Operation Iraqi Freedom) Registry Program (March 2005)
- "VA Health Care and Benefits Information for Veterans" is a new wallet card that nicely summarizes all VA health and other benefits for veterans, along with contact information, in a single, wallet-sized card for easy reference (available online at www.va.gov/EnvironAgents)
- In collaboration with DoD, VA published and distributed one million copies of a new short brochure called "A Summary of VA Benefits for National Guard and Reservists Personnel." The new brochure does a tremendous job of summarizing health' care and other benefits available to this special population of combat veterans upon their return to civilian life (available online at www.va.gov/EnvironAgents)
- VA Health Care Benefits Eligibility (*Link to VA Health Eligibility Home Page*)
- Special VA Health Care Eligibility for Veterans Who Served In Combat Theaters Fact Sheet, IB10–162 (December 2003)

Improvements in Health Care Eligibility

- Based on VA's experience providing health care to veterans of the 1991 Gulf War, VA supported legislation that provides enhanced enrollment (Priority Group 6) placement for veterans who served in a theater of combat operations after November 11, 1998. This authority provides a 2 year post-discharge period of cost-free care or services for conditions potentially related to this service.
- Provides full access to VA's Medical Benefits Package for recently separated combat veterans.
- Summarized in the brochure and poster distributed to all VA facilities called "Special VA Healthcare Eligibility for Combat Veterans," (available online at www.va.gov/EnvironAgents).

Poster:

Two Years Free VA Medical Care-New Combat Veterans (Sept 2006)

Special Reports on Gulf War Veteran Health Issues from the National Academy of Sciences Institute of Medicine (The full reports are available online at: www.nas.edu)

- Health Risk Factors by the National Academy of Sciences Institute of Medicine
- Gulf War & Health Volume 1 (2DoD): Depleted Uranium, Pyridostigmine Bromide
- Sarin, Vaccines
- Gulf War & Health Volume 2 (2002): Insecticides and Solvents
- Gulf War & Health (2004): Updated Literature Review of Sarin
- Gulf War & Health Volume 3 (2004): Fuels, Combustion Products, and Propellants
- Gulf War & Health Volume 4 (2006): Health Effects of Serving in the Gulf War
- Gulf War & Health Volume 5 (2007): Infectious Diseases

Attachment 2—Partial list of Training and Educational Materials on Gulf War veteran Health Issues for Health Care Providers, and Veterans and their Families

1. **New Clinical Guidelines for Combat Veteran Health Care:** In collaboration with DoD, VA developed two Clinical Practice Guidelines on combat veteran health issues specifically in response to health concerns of veterans of the 1991 Gulf War. These include a general guideline to post-deployment health, and a second dealing with unexplained pain and fatigue.

   - The new clinical guidelines give our health care providers the best medical evidence for diagnoses and treatment of illnesses that are a particular concern among veterans of the 1991 Gulf War.
   - VA highly recommends these for the evaluation and care of all returning combat veterans, including veterans from OEF/OIF.
   - Available online at www.va.gov/EnvironAgents under the heading, "Environmental Health Clinicians."

2. **New VA "War-Related Illness & Injury Study Centers" Specialize in Health Care for Combat Veterans with Difficult to Diagnose Illnesses:** In 2001, VA established two new War Related Illness and Injury Study Cen-

ters, or "WRIISCs" as they have become to be known, at the Washington, DC, and East Orange, NJ VAMCs.

- Today providing specialized health care for combat veterans from the 1991 Gulf War and other combat deployments who experience difficult to diagnose but disabling illnesses.
- Concerns about unexplained illness are seen after all deployments including OEF/OIF, but we are building on our understanding of these illnesses. More information available online at www.va.gov/EnvironAgents under the heading *"WRIISC Referral Eligibility Information."*

3. Expanded Education on Combat Health Care for VA Providers: In addition to the programs already described, VA has developed several Veterans Health Initiative (VHI) Independent Study Guides and other materials relevant to veterans returning from Iraq and Afghanistan:

- "Preparing for the Return of Women Veterans from Combat Theater," Under Secretary for Health Information Letter IL 10–2003–011, provides guidance to VA health care providers in planning and projecting special care needs for women veterans who have served in combat, including the 1991 Gulf War and from OEF/OIF.
- "A Guide to Gulf War Veterans Health" on healthcare for combat veterans from the 1991 Gulf War. The product, written for clinicians, veterans and their families, also remains very relevant for OEF/OIF combat veterans because many of the hazardous exposures are the same. Although still current, this clinical practice guideline is scheduled for updating in 2008.
- "Endemic Infectious Diseases of Southwest Asia" provides information for health care providers about the infectious disease risks in Southwest Asia, particularly in Afghanistan and Iraq, including for veterans who served in the 1991 Gulf War and OEF/OIF. The emphasis is on diseases not typically seen in North America.
- "Health Effects from Chemical, Biological and Radiological Weapons" was developed to improve recognition of health issues related to chemical, biological and radiological weapons and agents, in particular, in relation to service in the 1991 Gulf War and more recently in OEF/OIF.
- "Military Sexual Trauma" was developed to improve recognitions and treatment of health problems related to military sexual trauma, including sexual assault and harassment, in any deployment.
- "Post-Traumatic Stress Disorder: Implications for Primary Care" is an introduction to PTSD diagnosis, treatment, referrals, support and education, as well as awareness and understanding of veterans who suffer from this illness.
- "Traumatic Amputation and Prosthetics" includes information about patients who experience traumatic amputation during military service, their rehabilitation, primary and long-term care, prosthetic, clinical and administrative issues.
- "Traumatic Brain Injury" presents an overview of TBI issues that primary care practitioners may encounter when providing care to veterans and active duty military personnel.
- All are available in print, CD ROM and online at www.va.gov/NHI.

4. New VA "War-Related Illness & Injury Study Center" focusing on Combat Veterans with Mild and Moderate Traumatic Brain Injury: Based upon the success of the existing WRIISC program, established in response to health care needs of veterans returning from the 1991 Gulf War, VA recently established a new War-Related Illness & Injury Study Center (WRIISC) to respond the health care needs of new combat veterans suffering from mild to moderate traumatic brain injury. This third WRIISC will be located at the Palo Alto VA Health Care System.

- Improvised Explosive Devices, blasts, landmines and shrapnel account for a significant proportion of combat injuries seen from the conflict in Iraq and Afghanistan today—many of these result in some degree for traumatic brain injury.
- Many of the long-term chronic health effects reported for traumatic brain injury look like the sort of difficult to diagnose and treat illnesses currently being treated by the WRIISC programs today.
- The recently announced new WRIISC at the Palo Alto VA Health Care System (HCS) will take advantage of their unique assets including their Poly trauma Unit, interdisciplinary program on blast injuries that integrate the medical, psychological, rehabilitation, prosthetic needs of injured service Members, traumatic brain injury, spinal cord injury, blind rehabilitation post

traumatic stress disorder, and research into new and emerging areas of combat injuries and illnesses.

- The specialized clinical programs of the Palo Alto HCS will be enhanced and complemented via collaborations with the specialized clinical programs of a new Palo Alto WRIISC, and offer enhanced access to these clinical services to younger and new combat veterans across the country.

5. Special DU program: Gulf War veterans (as well as OEF/OIF veterans) concerned about possible exposure to depleted uranium can be evaluated using a special DU exposure protocol that VA began after the 1991 Gulf War.

- This program offers free DU urine screening tests by referral from VA primary care physicians to veterans who have concerns about their possible exposure to this agent.
- Gulf War and OIF veterans are eligible to participate in the VA DU evaluation protocol/screening program for Gulf War and OIF veterans.
- OEF veterans are eligible to participate in the VA DU evaluation protocol/screening program for non-Gulf War veterans.
- In response to health concerns about new combat veterans with retained embedded fragments from combat injuries in Iraq and Afghanistan, including blast injuries from improvised explosive devices, VHA is establishing the Toxic Embedded Fragments Surveillance Center (TEFSC) at the Baltimore VA Medical Center. Lessons learned from the Baltimore VA Depleted Uranium program show that retained metal fragments are not inert in the body and may change over time to produce potential toxic health effects. Such effects maybe minimized and managed through careful ongoing medical surveillance.

6. VA Gulf War Registry Examination Program:

- VA's Gulf War Health Examination Registry is one way VA tracks the special health concerns of veterans.
- Open to any veteran who served on active military duty in Southwest Asia during the Gulf War which began in 1990, and continues to the present including Operation Iraqi Freedom.
- Quarterly teleconferences with VA Gulf War Registry Health Clinicians and Coordinators.
- Eligible veterans receive a free specialized and comprehensive health examination with blood work, urinalysis (EKG and chest x-ray where medically indicated) and answers to questions relating to any environmental exposures.
- Every VA medical center has an Environmental Health Clinician and a Coordinator assigned to assist veterans in obtaining health registry examinations.
- VA Environmental Health Clinicians and Coordinators receive special training in Gulf War veteran (and other) health issues, including quarterly conference calls with the Office of Public Health and Environmental Hazards.
- As of August 2007, 101,057 veterans from the 1991 Gulf War have taken advantage of this free examination, as well as 7,325 veterans from OIF.

Attachment 3

Recent Annual Reports from the Washington, DC and East Orange, NJ VA War-Related Illness & Injury Study Centers (WRIISCs)

[This above report is being retained in the Committee files.]

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